

Centering Diversity; An ethnographic dissection of hemophilia care

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ABSTRACT

In this paper, I describe my entry as a 'change agent' in the dynamic site of a hemophilia care center (HCC) in a Dutch university hospital. I discuss the importance of using participant observation to create insight into the interpretative flexibility of the site, by showing the presence of diverse interpretations by various actors on different moments of 'what the HCC is' and what it means to 'make it work'. This reality contributed to a variety of roles that were ascribed to the researcher – a process which I took as a valuable source of information on the site. I conclude that, for interventionist research in a complex setting, it is of utmost importance to use a methodology that sensitizes the researcher for the different and changing views that exist on that setting. This allows one to become aware of the various roles that one is asked to play, and the solutions one is expected to come up with. With this sensitivity, a researcher can choose to intervene by giving voice to a certain interpretation, or at least avoid suggesting solutions that are bound to fail because they are contradictory to interpretations of strong actors on the nature of the setting.

Keywords

Ethnography, interpretative flexibility, ethnographically informed IT design, hemophilia care centers

INTRODUCTION: CENTERING HEMOPHILIA CARE

Hemophilia is a rare hereditary clotting factor disorder that is found in some 1500 people in the Netherlands. These patients are divided into three groups: light, mild and severe hemophiliacs. This division is based on the level of coagulation factors that is found in the blood, and patients in the various groups may experience substantial

differences in the consequences of their disease and treatment. Whereas a middle-aged patient with severe hemophilia may suffer from immobility due to damaged joints as a result of sub-optimal treatment during childhood, and may easily use up to €50.000,-- worth of coagulation factor concentrates, a young patient with light hemophilia may hardly ever notice any effects of his¹ disease nor need to take any medication. In the Netherlands, virtually all severe patients, and some of the mild ones are on home treatment. This means that they are trained in diagnosing and administering medication themselves, without having to depend on healthcare professionals for their daily treatment.

As a consequence of the variety among patients, care providers have indicated that there is a need for combined care from a hematologist, medical social worker, orthopedic surgeon, medical psychologist, physiotherapist, rehabilitation doctor and oral surgeon [9].

With this diverse and small group of patients needing complex treatment with expensive and scarce medication², the Dutch Ministry of Health in 1999 proposed to appoint hemophilia care centers (HCCs) to concentrate the care and provide this multidisciplinary treatment [3]. This was to prevent the scattered care leading to sub-optimal treatment. The policy that set the standards for the desired care was based on the consensus on hemophilia treatment as constructed by healthcare professionals [12]. This consensus was initially composed to indicate 'ideal' treatment – while professionals realized that many a times

¹ The use of 'he' and 'his' is, in regard to hemophiliacs, not a sign of sexist language: patients can only be men. Women can merely carry the disease.

² Approximately 80% of hemophiliacs worldwide are not receiving any form of medication. The vast majority of these patients live in 'developing' countries.

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reality would be less manageable – but is now taken as the norm that the HCCs should live up to. The boards of directors of various hospitals were asked by the Ministry if they wanted to be candidates for the status of the HCC, and after a selection, sixteen centers were appointed. Since it had been stated from the beginning that no extra budget would be allotted for the development of the HCCs, nor for providing the care, the centers now faced a substantial challenge; to change the organization and quality level of care to meet their self-set aims of ideal treatment, without any extra means being available.

The idea was expressed that a part of the challenge could be faced by developing and introducing certain forms of information and communication technology (ICT). Four aspects needed to be dealt with according to the internist-hematologists at the HCC. First, a multidisciplinary care team was to be put together by installing protocols and by facilitating communication among members. The idea was that, for such a care team to function properly, participants should have access to the patient data and therefore an electronic patient record (EPR) was considered of importance. This was the second aspect. Thirdly, improving communication with patients was seen as instrumental in optimizing home treatment and the Internet was seen as a technology that could support such developments. Last, the logistics and registration of the coagulation factor concentrates needed to be improved, if possible via barcode scanning of medication that would directly be registered into the EPR. It was in this setting that I entered one of the HCCs at a Dutch university hospital. Being interested in how organizational and technological changes are brought into being and in ICT development in healthcare, I started a study on how solutions were constructed for the problems that were seen as fundamental. This was not a distant perspective on developments that were instigated by other actors: in the process of providing solutions I was to have an active role. I entered the setting as a ‘change agent’ and had the explicit aim of supporting and bringing about transformation.

The interventionist nature of this project stems from the idea that action and the development of theory can support each other. The apparent relationship to action research and how my approach differs are beyond the scope of this paper. In this article, I will focus on the advantages of using ethnographic methodology in a highly flexible research setting. I will discuss the importance of using participant observation to create insight into the interpretative flexibility that is found when dealing with a dynamic institution. I will do this by showing that diverse interpretations by various actors on different moments of ‘what the HCC is’ and what it means to ‘make it work’, contributed to a variety of roles that were ascribed to – or chosen by – the researcher. I will conclude that, for

interventionist research in a complex setting, it is of utmost importance to use a methodology that sensitizes the researcher for the different and changing views that exist on that setting. This allows one to become aware of the various roles that one is asked to play, and the solutions one is expected to come up with.

ETHNOGRAPHY AND CONTROVERSY

Controversy and change have since many decades been a key interest for researchers in the field of Science and Technology Studies (STS). While initially there was a strict separation between the context and the content of science and technology, in the 1970s a shift took place within this field. Several researchers started seeing any encountered difference between social aspects and outcomes of technoscience as produced during the design process. The separation of ‘the social’ and ‘the technical’ itself was considered to be constructed, and therefore this perspective has been called ‘radical constructivism’ [6, p. 72].

A method that was embraced by researchers working from this perspective is ethnography. They found this approach suitable to show how order is constantly created by making certain perceptions on reality more plausible than others. The central question in such studies is no longer ‘why’ controversies find closure and stabilize, but ‘how’ this happens. Where STS researchers initially “used the most outdated version of anthropology” (10, p. 146)³ of trying to be a ‘fly on the wall’, there has been a substantial development in which the interpretation has shifted to participant observation. Here the definition of ethnography is much closer to that used by anthropologists: “[Ethnography] means talking to and interacting with people, and ultimately attempting to understand their symbolic worlds and *social action*” [7, p. 4, italics in the original]. It has to be stressed here that these ‘symbolic worlds’ are constructed, but not merely *socially* constructed. These worlds are made up of hybrid elements in which both human and non-human actors perform their ordering activities. I will turn to examples of this construction process in the section called ‘Countless Care Centers’. Similarly, there has been a strong influence of ethnography on the field of Computer Supported Cooperative Work (CSCW). Though there is an admitted complication in “enabling designers to *utilise* ethnography”, it is the “ability of ethnography to describe a social setting as it is perceived by those involved in the setting (the archetypal ‘users’) that underpins its appeal to designers” [8, p. 147, italics in the original].

Because of the fruitful studies that have come from STS of complex, changing and controversial settings using

³ Quoted in Hess, 1992 [7]

ethnography, and the interesting cases from the field of CSCW integrating ethnography and design, I also adopted the approach of participant observation to construct my ordering of the HCC. The balance of participating or observing has shifted many times⁴, since I was also expected to contribute to solving the problems that were perceived. The ways in which I did this were very diverse as a result of the insight that intervention is a strategic activity manifesting throughout a research project. It is not just the closing phase following the period of doing fieldwork⁵. The fact that various actors expected me to intervene influenced the number of roles that I was expected to play according to them. Before turning to these roles, I will first dissect 'the HCC'.

COUNTLESS CARE CENTERS

A concept that has been coined to describe the existence of multiple perceptions on a technology, an institute or a scientific fact in an early stage of its development is 'interpretative flexibility' [1]. This concept can be used to avoid "any implicit assumption of linear development" [2, p. 6], which is one of the main aims of STS research. Having originated from the social construction of technology (SCOT) approach, it has mainly been seen as a way to describe how various 'relevant social groups' view an object differently. Here however, I would like to stress that the HCC was not just seen differently by various groups, but also differently by the same actors at various times. When realizing the variable nature of interpretations over time, this concept is highly applicable to the setting of the HCC, and allows me to tell the story on how the interpretations differ. It will become apparent that the change process itself was instrumental in the variation of interpretations.

Questions that proved to be illustrative of the interpretative flexibility were: 'What is the HCC?' and 'How do we make the HCC work?' The clearest, and most explicit answer to these questions came from a representative of the Dutch Association of Hemophilia Patients. This informant reacted as if bee-stung: "What do you mean 'to make it work'? It is already there! The Ministry has appointed them, so they already exist." For her, discussing the present functioning of the care center was out of the question: it *already existed*. All the aims were laid down, and now it was just up to the care providers to live up to these standards.

Initially, a rather opposite reaction came from the internist-hematologist, who was my key contact at the center. He

stated that we had to be very careful, because: "if we don't make the HCC work, we may be closed down. I think that is a real risk, and the more so for some smaller centers. The only center that would then remain is the Van Creveld". The fear of being closed down, and the resulting perception of the HCC as a *threatened unit* was initiated by the way the implementation of the policy by the Ministry was presented. The initial demands were that a formal examination with direct consequences for the continuation of the status of the HCC would follow within one year. Since the problems were substantial, this informant seriously doubted the chances of passing the test.

The perception on the viability of the center altered after a big reaction came from medical professionals. They expressed their discontent with the state of affairs concerning the implementation of the policy in strong words to the Ministry. This changed the ministerial aim of 'examining' the centers from a formal exam into drawing up an inventory, which diminished time pressure to shape the HCC substantially. This also seemed to transform the perception of the internist-hematologist on the HCC. Instead of the center being threatened, he became eager to show it as an *efficient unit* in the hospital. This interpretation came to the fore when we were discussing a paper I had written for the hospital pharmacy to indicate the amount of finances that were being lost due to sub-optimal registration and logistics of coagulation factor concentrates. I carried out this investigation in order to generate budget to employ an extra person at the HCC dealing with medication, and to increase my credibility at the site (see the section 'Nine Lives in a Hospital'). The internist-hematologist was called to the Board of Directors of the hospital after they received a copy of the survey that he had filled out and sent to the Ministry as part of the inventory. He had filled it out quite strategically, focusing more on problems than on achievements and now assumed he would have to justify himself for the way he had represented the hospital. He said: "I would like to bring this paper along to the Board of Directors. It is good to show them that we do quite a bit more than just filling out inventories here!" The very changes that were taking place in the setting enabled him to adjust his interpretation of the HCC, and state that we were turning it into an efficient unit.

When I arrived, the 'multidisciplinary care team' that I expected to find turned out to be nothing but a number of individuals, not meeting at all, not knowing what procedure to follow in case a hemophiliac would show up; not showing any characteristics of a 'team'. During my stay there, the care providers of the team started meeting, and discussing patients together. Also, a protocol folder was created for all disciplines. This turned out to be a highly constitutive activity for healthcare providers since it made the HCC more and more tangible in the hospital

⁴ A common problem for ethnographers, which is dealt with elaborately in Hughes et al., 1997 [4].

⁵ The point made here is further developed in Zuiderent, 2002 [15].

environment. Even though it proved difficult to implement the protocols they did give guidance to the discussion among the various disciplines. For the professionals from other disciplines, the HCC was starting to work this way: the *care team* started functioning.

Upon arrival, one of the important activities of the hemophilia nurse was her dealing with all the contacts with industry. She would maintain her own stock of coagulation factor concentrates, get product information, order medication and receive the sales managers when they came to visit. She stated that this was definitely improving the quality of care, and should be a task that should be carried out by her. She realized that most patients hardly ever saw a doctor, and in general administered their own medication. Therefore providing them with the proper medication was the most important function of the HCC. It made her situation on the outpatient clinic of which the HCC was part special, and it defined the working of the HCC as operating her *own shop*.

This definition was a thorn in the flesh of the head nurse of the integrated outpatient clinic hematology/oncology. When giving me a reprimand after a meeting (see the section 'Nine Lives in a Hospital') she stated that it was of utmost importance that: "we shouldn't return to the situation where the hemophilia is something completely different, with different privileges and all. That was the case when I came here, and I was told that was exactly the problem with this clinic!" For her, making the HCC work was to keep it as an *integrated unit*. She tried to install this interpretation by rotating the nurse as much as possible to the other positions in the clinic, and by stressing in meetings that officially there doesn't exist such a thing as a 'hemophilia nurse' in the Netherlands. She also insisted on the fact that there was no permanent function for a nurse dealing with hemophilia: the work was just part of the activities at the outpatient clinic.

However dearly she may have wanted to describe the clinic as integrated, other actors enforced the definition of the center as a *separate unit*. One of the decisions made in the working group that was formed for the HCC⁶ was that a PC was needed for its development. The perception of the head nurse that the center is based in, and part of an integrated outpatient clinic for hematology/oncology was challenged by a non-human intervention. In the clinic the nurses work with 'dumb' terminals that provide access to the hospital information system (HIS) through the hospital's mainframe computer. The PC was to be placed on the desk where the hemophilia nurse was sitting most of the time, and was to replace the terminal. After having decided on the need for a

computer however, it turned out that the network box to which it was to be connected was a dummy: it was merely a box, with no cable leading to it to connect it to the hospital network. As a result, the whole ceiling would have to be opened in order to provide such a connection. In a crowded outpatient clinic, this is close to disastrous, and the head nurse quickly arranged for a room to be allotted to the HCC. Though the head nurse was trying to factualise her interpretation of the center as integrated, the alliance of the PC and the box provided the irrefutable argumentation for obtaining a separate place designated to the HCC.

The discussion on the logistics and registration of the coagulation factor concentrates led to another interpretation of the HCC. Among participants of the working group, the view became dominant that the position of the hemophilia nurse would have to change. Not only were her tasks concerning registration seen as secondary to a nurse's job – and this in a clinic with a serious lack of nurses – it had also turned out to be costly since registration was not optimal. It was decided that an extra position would be claimed for an assistant pharmacist to be employed. A part of the time that would become available was to be used for installing a nurse-led home treatment clinic. Before this was actually operating, the nurse one morning asked me: "Are you having any appointments today? Because I have my first nurse-led consult today". She said it with a lot of enthusiasm, and what it means to make the HCC work slowly seemed to shift from running her own shop to creating an intensified *nurse-patient relationship*.

Based on these observations on the different ideas on what it means to make the HCC work, the range of interpretations of the center can be seen in Figure 1.

These various interpretations can be seen as part and parcel of the early stage of the development of the HCC. Since not much has been agreed upon, there is much room for interpretation, and while closure starts to take place, interpretations are changing accordingly⁷. This variation is not without consequences for me, as a researcher, who entered the setting as a change agent, and is seen as someone who can help materialize a certain interpretation. As a result of this there was a large array of roles that I was expected – or trying – to play. Besides that, some roles seemed to emerge due to my prolonged stay as an ethnographer. To these various roles and their different origins I will now turn.

⁷ This does not necessarily mean that actors start agreeing on the interpretation: actors may fight even harder to make their interpretation heard once another perspective is gaining terrain.

⁶ Another constitutive activity.

CLOTHES MAKE THE MAN: GET A LARGE WARDROBE!

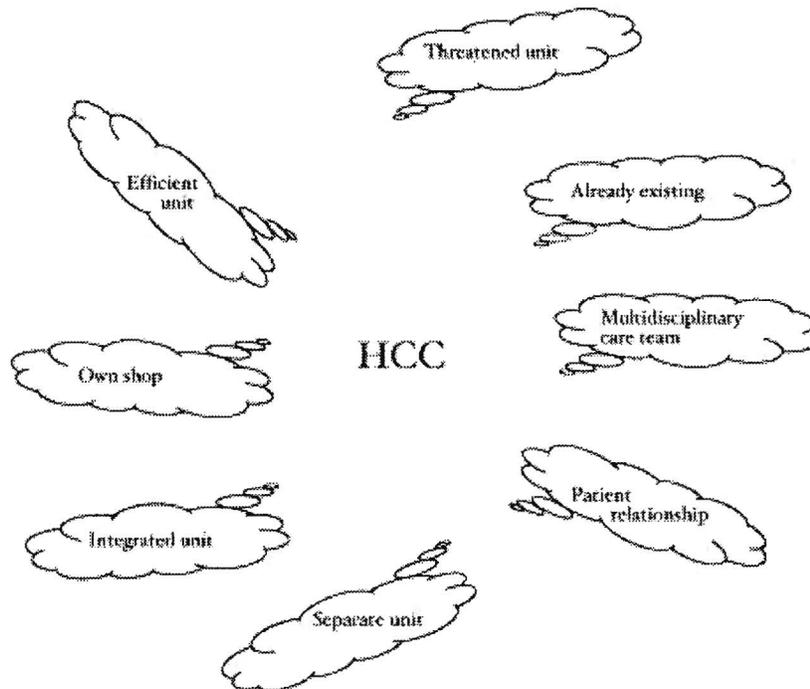
When I entered the research setting, it soon became apparent that the level of flexibility required by me was substantial. Due to the various ideas of what the center is, and the stakes that are involved for different actors, I found that many a times roles were being attributed to – or enforced on – me that stemmed from a specific interpretation of the HCC. Also some roles seemed to arise as a result of my presence as an ethnographer. And besides all this, of course, I tried to position myself and adopt roles strategically. For this, an instrument that was at my disposal, or rather, that I tried to use was a large wardrobe. This is a well-known ally of an ethnographer when facing various groups within one setting⁸. But of course, I could only do so much to divert the attention of my informants from the roles they wished to ascribe me.

on the setting I was researching. This shift in perspective turned a stressful situation into a rich source of data. The anthropologist Mascarenhas-Keyes states on this issue that: “since stress seems to be a *sine qua non* of fieldwork (...), rather than escape from it I suggest that we could usefully integrate it into fieldwork methodology” [11, p. 189]. Without wishing to elaborate here on the way she relates this issue to concepts from psychoanalysis, I did find the approach to be helpful in clarifying the roles themselves, and the information they gave me on the different interpretations of the HCC and of me.

Nine Lives in a Hospital

In one of the first weeks of the project the internist-hematologist suggested that I should visit some of the other centers to compare existing organizational practices. He made a phone call to a colleague at the largest HCC in the

Figure 1: Interpretations of the HCC



At first, I was rather cautious of these different roles, and felt somewhat threatened by the idea that my informants were trying to ‘use’ me for their various goals. However, it didn’t take long for me to start taking comments on my work and roles being ascribed as valuable sources of information

⁸ For an interesting account of the way dress was used in order to deal with different groups in an anthropological study in Goa, see Mascarenhas-Keyes, 1987 [11].

Netherlands in which he said: “We have a *logistics manager* employed here, who would like to take a look at the whole logistics of coagulation factors at your place”. I interpreted this remark as an indication that he was positioning himself in a strong way towards this other center. He was still seeing the HCC as a threatened unit and wanted to show that we were doing all we could to get the center organized. The role of an added direct employee was strengthening his position much more than portraying me as an external researcher.

A somewhat similar, but more broadly defined role was that of the ‘*project leader*’ in the HCC. This was a role that I

partly took myself, and that simultaneously was attributed by the internist-hematologist. My choice for this role became apparent just before the first meeting of the project group. Since the aim of this meeting was to present possible directions to pursue our organizational change, I had attempted to enhance my credibility by dressing more formally than in the time prior to this meeting. The suit I was wearing was – by managers well known – an ally in the attempt to start an organizational change. As I walked in, the internist-hematologist saw I had dressed more formally, and being quite content his only remark was: “Very good! I will buy you a tie some day”. Apparently he wanted to stimulate this development into a more managerial position for me, seeing the need to do much work to survive as a center. Therefore this role was related to his interpretation of the HCC as a threatened unit. By stating that I do own a tie, but that I just don’t like to wear one, I indicated the boundaries of my managerial intentions.

In a very different setting, the head nurse called me into her office right after a meeting. When I entered she closed the door behind me saying: “So, that door we *fully* close...”. After this, she gave me a reprimand like one can only give to an employee that’s much lower in the hierarchy and that has stepped out of line. She had been quite displeased with the tone of something I had said during the meeting, and said she didn’t appreciate me being cynical at all. Besides the fact that it was highly puzzling to me to understand what she meant – since I hadn’t intended any cynicism during the whole session – it was interesting to be seen as an ‘employee’ all of a sudden. For this scolding to take place a high level of integration in the setting was needed. This may very well have occurred due to my prolonged presence in the outpatient clinic and direct contacts with the hemophilia nurses, and therefore it could be a direct result of the ethnographic approach. But besides that, it seemed to indicate that I formed somewhat of a threat to her interpretation of the HCC as an integrated unit. Since my arrival, the separation of the center from the outpatient clinic had become more material, and it seemed like she wanted to strengthen her grip on the developments through stressing my inferior status. This became even more apparent when the conversation ended, and she stressed the importance of maintaining an integrated clinic to avoid the problems that she faced when she started her work (as mentioned in the section ‘Countless Care Centers’).

A role that I adopted mostly in the early phases of the project was that of ‘*ignorant eyes and ears*’. Since this phase consisted mainly of observing the medical practice, it was important to gain the confidence of the nurses. Therefore, in this phase, a substantial modesty was needed. This role was performed by asking many questions, by following the nurses wherever they went, not interrupting them when they were engaged in conversation, and by

wearing leisure wear. Being surrounded by healthcare professionals in their white ‘uniforms’ made any possible sign that clothing might project much more visible. The role was also ascribed by the internist-hematologist in regard to the multidisciplinary care team. The changes that were taking place there were mainly resulting from the initiative of the internist-hematologist, and he didn’t seem to need me in the organization of the care team. However, every now and then in our weekly internist-hematologist meetings I would ask him how things were developing with the team, and he would explain to me about the protocols, etc. The fact that here he didn’t expect an explicit role from me, in fact enforced this distant role.

As mentioned above, at some point in the project I was carrying out an investigation of financial and procedural consequences of the practice of the registration of medication. This was mainly because it became clear that the existing process of ordering and registering coagulation factor concentrates was problematic. The hemophilia nurses took care of the entire process, and since their primary focus was on providing care to patients, erroneous registration was unavoidable. This made the process costly while simultaneously frustrating the primary care process⁹. Though participants of the working group of the HCC agreed with the importance of separating activities for the sake of registration and process-supporting activities¹⁰, they also indicated the pertinence of being able to underline such a point with financial data, and suggested that I would carry out the investigation to obtain such data. It seemed of importance for my legitimacy in the setting to fulfill this task, since a relatively small investment of time could lead to substantial managerial changes if an extra member of the staff could be employed with the money that was traced. Therefore, I saw not much of a choice other than to take up this quite foreign role of ‘*forensic accountant*’. When the internist-hematologist wanted to use the document I had produced to show the Board of Directors that he was turning the HCC into an efficient unit, it became apparent why this role was ascribed to me, and similarly, the role itself made it more clear how the center was being seen.

During one of the observation sessions at the HCC, I was present at a follow-up clinic for children with hemophilia and their parents. I was sitting in the corner, taking notes and after some time the doctor had to leave the room for a few minutes. Instantly the parents started asking: “Is this for

⁹ For an analysis of the problematic nature of integrating registration for secondary purposes in the primary care process, see Van der Lei, 1991 [13]

¹⁰ An important distinction suggested by De Kluiver et al., 2001 [5].

your studies?" I briefly answered that it was for my work at the HCC, trying to cause minimal intervention in the setting, for this seemed appropriate at this time. Similarly, this role of being a *student* was attributed by some of the employees of the hospital. An oncologist who had seen me wandering around the outpatient clinic for some weeks asked me whether I was researching their clinic for my MA thesis. Apparently my informal and prolonged presence and my young age made him categorize me as a student. Finally, this role was also ascribed by the internist-hematologist in the beginning of the project. Because he saw it as desirable that I would understand hemophilia as a disease soon, he started lecturing me on the topic. Clearly he wished to invest a substantial amount of time into my training at the beginning, so I could get started soon. I thought the lectures were extraordinary, since he also could have given me a handbook or folder on hemophilia. But the urgency he experienced due to the threat of being closed down as a HCC made him invest all this time and effort.

Where these roles all seemed to stem from, or at least to be related to specific interpretations of the HCC, there were also a number of roles that were ascribed while stemming from other ideas or situations. A role that was attributed after several months on the site was that of *adoptive nephew*¹¹. This became apparent after a protocol meeting, where a presentation of the HCC project was given to all hematologists of the outpatient clinic. In this the observational part of the ethnographic method and the lectures on hemophilia that the internist-hematologist gave me paid off during the discussion with the hematologists. I found that I had gained enough insight into hemophilia to be able to discuss on an equal level with the professionals¹², and after that meeting, the internist-hematologist was quite contented with the proceedings. He complimented me in a fatherly manner: "I am really impressed with the medical knowledge you have gained so far". After this, it was much easier than before to contact the internist-hematologist, even when he was busy. This role also came to the fore during the period in which I was involved in some projects that were not dealing with the core of my research. He then said, in a comforting tone: "But I remember so well from my own research; many times I put in all time and effort and it didn't lead to anything. You will just have to realize that this is part and parcel of Ph.D. research." This role may be interpreted as a result of the intense collaboration in this

¹¹ A role that has also been observed in an action research project in Waring, 2001 [14].

¹² Note that hemophilia is a rare disease with only some 1500 patients in The Netherlands, and that for most hematologists their knowledge of treating such patients is rather basic.

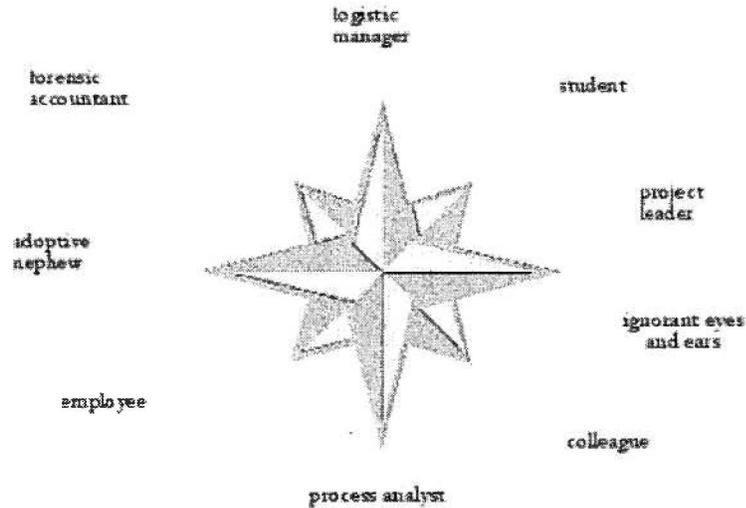
project, and has also been interpreted as being gendered. Waring [14] has described how her role as a female action researcher led to substantially different and more problematic contact with the actors at her setting than the later introduced young, male IT programmers, who were adopted instantly.

After several months the hemophilia nurse – who was by then my roommate in the hospital – was working on a sheet of lab results as she suddenly turned around, asking a question I didn't understand. She mentioned something about the lab result she was reviewing, but since I looked truly lost, she explained again. Finally I realized that what she was asking had nothing to do with hemophilia, but was related to one of her other tasks – about which I didn't know a thing. She had made a calculation on a drug dose based on a previous lab result and now she was wondering whether or not she should recall the patient to prescribe a new dose. To win some time I asked: "How long is such a prescription valid?" "Three weeks", she answered "So should I call him or not?" All of a sudden I was being addressed as a *'colleague'*. The only thing I could do was to answer that I didn't have a clue, and that I wasn't the right person to ask, but her perception of me being a colleague indicated the high level of integration into the medical setting. This probably resulted from my prolonged presence as an ethnographic researcher.

After having produced a first working document in which I made a preliminary assessment of the problems that were perceived and the solutions that might be aimed at, I discussed it with the project group member of the hospital IT department. My aim had been to provide a discussion paper that could clarify what positions were prevailing and what differences may exist; not to provide an accurate paper 'representation' of the situation. Since an organizational model was what this actor had hoped for, he stated that he was quite disappointed: "I expected that, since you had been walking around here for some time, you should have been able to give quite a detailed process description by now. You should have been able to show us where we are now, where we should end up, and the steps that are needed to go from A to B. Instead I see this report, that is very unclear to me!". His dissatisfaction could be explained by the fact that he wanted me to be a *'process analyst'*. This would be a role that he could relate to when wanting to structure and automate certain procedures. A model of the work would have made 'the center' tangible and manageable for this actor. However, his inclusion in the setting was not high enough to be able to see this as a veritable interpretation of the HCC. The role stemmed from his professional practice, that he tried to align me to.

Based on the observations of the different roles that were ascribed to me, and that I tried to adopt myself, I can draw

Figure 2: Roles ascribed and adopted



the inscription of Figure 2.

The relationship between the interpretations of the HCC and the roles that were ascribed becomes apparent when combining Figure 1 with Figure 2.

With the thus created Figure 3, I wish to indicate that the roles that were ascribed by actors in this research setting proved highly informative of the interpretations that were present among those involved in the HCC. The three remaining roles of colleague, adoptive nephew and process analyst did not emerge due to a specific interpretation of the center, and this indicates that there are other factors to be taken into account when studying a setting, such as the gendered nature of relationships and roles.

DISCUSSION: DISSECTION AND SELECTION

The study at the HCC is still in its early stages. Though some changes have been set in motion, it can hardly be stated that the initial goals of putting together a multidisciplinary care team including all agreements with hospitals in the region, optimizing home treatment, developing an electronic patient record (EPR), and optimizing the logistics and stock management of coagulation factor concentrates, have been achieved. I mainly used the first period of the project to get a good feel for the setting, for problems that are perceived, and the variation in interpretations. The method of participant observation has been highly instrumental in obtaining information on the HCC and on the numerous stakes that are involved. The insight thus gained in both the content of

the work, and in the diversity of the setting will have its consequences for the solutions that I will propose.

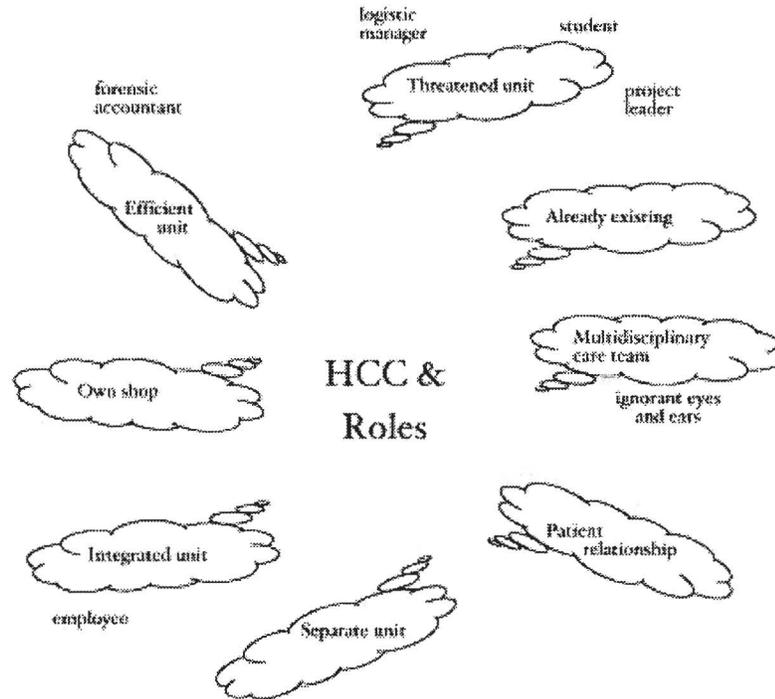
When entering a complex site, where change is to take place, it can be expected that there is a high level of interpretative flexibility. First, opinions may differ on whether or not any change is needed. And second, if the change is desired – or, as in this case, enforced – an array of preferred directions may be present. When a researcher is asked to assist as a change agent, it is of utmost importance that s/he first gets a thorough understanding of the *problematique* that is to be encountered. Any solution that is proposed will be favoring a certain interpretation of the setting, and therefore exclude another version. Realizing this gives the researcher the moral obligation to become aware of stakes and interpretations. As I have tried to show in this paper, ethnography is a very suitable methodology for obtaining this information. Especially the reactions to my presence and the roles that were attributed proved highly illustrative and informative for dissecting the site. This allows me to take the complexity of the setting into account when working on solutions for perceived problems. This may lead either to a specific choice to give a voice to a certain (group of) actor(s), as is seen in participative research strategies. But even if this is not the aim, then I can at least be safeguarded from suggesting solutions that look suitable on paper, but that will be encountered by many actors since it is contradictory to their interpretation on what it is to make the site work.

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Figure 3: Roles and interpretations of the HCC



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