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Client involvement in home care practice: a relational sociological perspective

Stinne Glasdam, Nina Henriksen, Lone Kjær and Jeanette Praestegaard

A sociologically inspired single case study was conducted, consisting of three weeks of observations and interviews. The study has a focus on the relational aspects of home care and the structural, political and administrative frames that rule home-care practice. Client involvement is shown within four constructed analytical categories: ‘Structural conditions of providing and receiving home care’; ‘Client involvement inside the home: performing a professional task and living an everyday life’; ‘Client involvement outside the home: liberal business and mutual goal setting’; and ‘Converting a home to a working place: refurbishing a life’. The meaning of involvement is depending on which position it is viewed from. On the basis of this analysis, we raise the question of the extent to which involvement of the client in public home-care practice remains limited.

Key words: case study, elderly, field study, home care, involvement, neo-liberalism.

This article focuses on involvement of clients who receive (permanent) help at home from healthcare professionals to enable their everyday life. Around the mid-1950s, the British psychiatrist Balint wrote about ‘patient-centred medicine’. The idea was that the patient’s unique individuality had an impact on disease and treatment, which in turn had an impact on the physician’s work (Balint 1957). Through the last 35 years, ‘client involvement’ has become a mantra within health policies, health curricula and healthcare institutions over many years, yet very little is known about how ‘client involvement’ is practised in home-care services. The aim of this article is to analyse ‘client involvement’ in practise seen from the positions of healthcare professionals, an elderly person and his relative in a home-care setting.

These days, the concept of client involvement has been revitalised as a mantra, for example in connection with the areas of rehabilitation and telemedicine, as a drive towards the topic increases (Sundhedsstyrelsen 2010). In the setting of home care, in Denmark as in other Western countries, there is an expectation of involvement of both the elderly and the professionals with regard to the legislative level, the local politician level, the organisational level, the management level, the professionals in practice and the clients (Friedman and Bino-Snell 2004; McWilliam et al. 2001; Henderson 2003; Dirita et al. 2008). Several national legislations, for example in Denmark, England, Finland, Norway and Sweden, state that clients have the right to be involved in their personal care and treatment (Indenrigs- og Sundhedsministeriet 2010; Lyttle and Ryan 2010; Rostgaard et al. 2011).

Public home-care service is a well-known offer in the Western world, but Denmark seems to be at the top of the statistics concerning people who receive that kind of help. Twenty-five percentage of people aged 65 or over get Home-
Care Service in Denmark compared, for example, to the Netherlands, where 21% of the elderly aged 65 or over receive this kind of help, UK 13%, Canada 10%, USA 3% (Huber et al. 2009). In Denmark, more than 60% of the elderly aged 85 and over are living in their own homes and receive professional home care (Nyt fra Danmarks Statistik 2010), and elderly people have been given free and practical permanent public home care since 1958, which seems quite unique (Rostgaard and Pfau-Effinger 2011; Rostgaard et al. 2011). All elderly people have the right to apply for assistance with personal care, house cleaning and delivery of meals at home. The local administrative home-care allocator is responsible for assigning the assistance according to existing laws and local standards and has the economical responsibility and authority in the municipality (Dahl 2005; Rostgaard and Thorgaard 2007; Ryberg and Kamp 2010; Sundheds- og Omsorgsforvaltningen 2011). This strategy is meant as a possibility for elderly people to stay as long as possible in their own home, which also implies financial benefits for the local authorities, as it minimises costs for construction of residential homes and operating costs (Odeén 2002; Rostgaard et al. 2011; Kröger and Leinonen 2012). On the level of Management, standards and guidelines are developed to ensure the client’s involvement in care and treatment while living as long as possible in one’s one home (Socialministeriet 2003; Ryberg and Kamp 2010; Sundheds- og Omsorgsforvaltningen 2011). In the Nordic countries, national legislation specifies that the local governments are responsible for regulating the quality of home-care services. They try to improve consistency and equity in access to and levels of home-care services, but in different ways. Sweden and Norway have standardised maximum levels of user charges. Sweden and Finland (and also England) have rights to assess home care, Denmark has standardisation of assessment tools, and Norway has other procedural rights (Rostgaard et al. 2011).

Reviews of international literature show that there seems to be a common agreement that client involvement in care and treatment is desirable, appropriate and necessary, but no consensus on how to interpret involvement on the part of the client in his own care and treatment. It is shown that the term ‘client involvement’ is frequently used in everyday language, in professional conversations and political debates, but without a clear definition, the term holds different meanings depending on who applies the term and in what context (Færch 2008; Grum 2008; Færch and Harder 2009; Lyttle and Ryan 2010). In the immediate, we have only been able to find a limited number of studies about client involvement in home-care service, a result which is confirmed by Wolff and colleagues (2009). Studies show that elderly persons expect to be met as unique individuals with personal expectations, wishes and needs, although many of them adopt a passive role in relation to healthcare professionals (Rostgaard and Thorgaard 2007; Kofod 2008; Florin et al. 2009; Thomasen 2009; Lyttle and Ryan 2010). Other studies show how the client–professional relationship is a power relation and how this influences the possibilities for client involvement in home care (Purkis 2001; Oudshoorn et al. 2007; Eloranta et al. 2008; McGarry 2010); caring for people in their own home does not necessarily mean that clients are involved in care and treatment decisions (Millard et al. 2006). It is further shown how relatives are caught between being actively involved in care tasks and decision-makings and being able to withdraw from such responsibilities (Hegh and Foss 2009; Stajduhar et al. 2010). One study shows how home modifications unfold as a negotiation between the professionals (and their working place) and the client and his wishes for his home (Johansson et al. 2009). There seems to be only one Danish study about how client involvement takes place in home-care settings, namely, in relation to dying at home. It shows how professionals’ construction of normative settings for acceptable behaviour on the part of dying people and their relatives is in contrast to practical client involvement in home care (Raunkiaer 2007, 2009). The empirical studies about client involvement in home care do not seem to embrace the political structure of which home-care service is a part. Therefore, the aim of this article is to analyse ‘client involvement’ as it unfolds in home-care practice in action, to understand what the concept means in this context.

METHOD

A single case study is designed consisting of one elderly person, who depends on healthcare professionals in his everyday life, his cohabiting wife and the formal healthcare professionals around him. This study is an analysis of an individual unit consisting of persons, relationships, events, decisions, etcetera, in a politically ruled healthcare system, studied by observations and interviews. The single case study is shown as a valuable method when used for the purpose of analysing how people frame and solve challenges in life. A single case can illuminate and explain the single unit for the purpose of understanding a larger class of (similar) units (Barzelay 1993; Armeto and Caren 2002; Gerring 2004; Flybjerg 2006; Thomas 2011).

Theoretical framework

The case study draws upon a critical sociological theoretical framework in the tradition of the French sociologist Pierre
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Bourdieu. Bourdieu explains how you must always study the issue(s) in a relational way that also takes into account the structural framework in which it unfolds. It means that you have to pay attention to the actors’ position and the power in the relationships in the specific context. By position, Bourdieu means the social position from which the person acts, speaks, thinks and lives, from which the social world is regarded and lived. Persons have an orientation – a practical sense – that produces outlines of discourses and practices. Whenever people meet, power is a condition for every relation. Power is here understood as to ‘be able to’ bring things in action (Bourdieu 1986, 1992). Bourdieu (1999) shows how the practices of the state have been modified as a result of the neoliberal reorganisation of the state in Western Europe in the 1970s and 1980s. He describes how people on both sides of the desk, for example teacher and student, are suffering because of the new misery that the market-oriented society has created. One of the purposes of the state is to control and manage the services that are not privatised or only partly privatised to ensure efficiency and financial profitability. Hereby, the neoliberal logic calls for the state to minimise the public employee’s degree of freedom to control them. In this study, home-care service will be understood as a practice of the state in a neoliberal society. The concept ‘Involvement’ will be analysed from the different positions of the actors and within this structural framework.

Recruitment

The case study took place in a Danish municipality of about 50,000 inhabitants. The leader of the Home-Care Department pragmatically selected one client with whom the field study could take place. This way of selection could be seen as problematic as the leader could be regarded as being part of the case. Implicitly, she could have preferences to favour one special case rather than another. On the other hand, it was the only possibility of selection due to the practical and economic resources of the project. We recognise, however, that this procedure is theoretically contrary to Bourdieu’s own way of selection of participants, where every participant is specifically chosen on account of his or her position in the studied field (Bourdieu 1999).

The general inclusion criteria we used for the appropriate participant for this case study were the following: age 65 and over; dependent on healthcare professionals to live in one’s own home; fluent understanding and speaking of Danish; and acceptance of the healthcare professionals involvement in the person’s everyday life. The client was not to suffer from dementia or aphasia. The client we included lived together with his wife in their own home during the field study, and, therefore, the spouse was also included. The recruited healthcare professionals included were those in the client’s understanding he had formal professional contact with. Two social and healthcare assistants, one physiotherapist and one administrative home-care allocator, with a background as an occupational therapist, were included.

Procedures of field study

A field study of three weeks duration was carried out in the fall of 2010 in the home of the elderly person in question. Appointments for suitable days for observations were made and, when needed, changed according to the family’s life and activities. The observations were conducted through eight days within the period from 8 AM to 10 PM. The researcher took field notes on a laptop, which evidently disturbed the observed less than the initial note technique with paper and pencil. The field notes were constructed using a schema containing the following categories: time, place, action – what happens, actors, conversation – verbal and non-verbal and the researcher’s immediate reflections.

The physical settings of the field study consisted of the house of the client and the clinic of the physiotherapist. The included persons in the study met in those places in different ways and with different agendas. Interviews with the participants were carried out. The interviews took place during the field study, when situations spontaneously offered the occasion, and in more formal settings. The spontaneous interviews were noted on laptop or recorded in notes according to the circumstances. The formal interviews took 1–2 hours and were performed using a semi-structured interview guide containing three categories: personal background; describe a typically day; describe the relationships between the elderly, the relative and the professional(s). The interviews took place according to the participant’s preference. The interview with the physiotherapist only lasted for 15 minutes, because he refused to take time off without being paid. The interviews were recorded and transcribed in full length.

Ethical considerations

The study followed the principles of the Codes for Nursing Research (Sykepleiernes Samarbeid i Norden 2003) based on the Helsinki Declaration (The World Medical Association 2008). Approval by the Danish National Committee on Health Research Ethics (2012) is not legally required for this kind of study. The study has been reported to the Danish Data Protection Agency, J.no. 2010-41-5125.
First, the leader from the Home-Care Department informed the client and his family about the project orally; next she informed the healthcare professionals in the client’s home. After they had all expressed interest in participating in the study, the researcher informed all of them, orally and in writing, about the case study, that all participation was voluntary and that they could withdraw at any point without explanation. Informed consents were obtained. Everyone involved in the project accepted the confidentiality of participants and location of the project. All data were anonymised and kept inaccessible to others than the researcher team. In publications, the study seeks to maximise anonymity when using illustrative quoted material. Individuals may be able to recognise themselves in the quotes, but names, person-specific job names and toponyms have been removed. Although full detail about the biographical and social context in which the client and all other actors in this case study would certainly have expanded the kind of analysis that Bourdieu’s critical sociological framework had in mind, these ethical considerations limit our capacity to report all the elements that may have shaped the actors’ positions. However, we consider the analysis to have theoretical relevance as we use the case study to reflect on the larger context of client involvement.

**Method of analysis**

First, a naive reading of the transcribed field notes and interviews was carried out to grasp the meaning of what the texts were about. Then, we focused on a relational understanding with particular focus on the relationships unfolding, what the different actors were doing and how, with specific focus on how ‘involvement’ was practised in action seen from the different positions of the actors. The texts were read through research questions such as: Who are the actors and what positions do they have in the situations? Who is meeting whom, where and how are they interacting and involving each other and themselves? Next, the analytical categories, as shown in the results section, were constructed on basis of both a structural level and the different arenas where the actors met, guided by the theoretical sociological framework. The texts were analysed within the constructed categories related to the concept of ‘client involvement’ as seen from the different positions of the actors.

**RESULTS**

The results of the analysis are presented below as seen through the lens of the relational sociological understanding. They therefore incorporate and set into play the different positions of the actors. In this way, the form of the presentation in itself reflects the analytical method.

**Structural conditions of providing and receiving home care**

The general political and local administrative system frames the possibilities for home care for an elderly person. The administrative home-care allocator has the position to assign and allocate the care on behalf of the administrative system and the law. This implies that an elderly person can wish for a certain kind of care but is subject to the interpretations made by the administrative home-care allocator who in turn is subject to structural, bureaucratic and administrative sets of rules. What concerns the treatment, which is ordered by the physician, the client can decide whether he wants the assistance from healthcare professionals or from his wife (if she agrees):

It would have been natural for her to take over. But I also think that he doesn’t want to have a dependency of her. Or she might not want to be tied to him. […] (The client) often expresses sadness about being too dependent of her […] and also of us. […] It must be harder to feel dependent of one’s wife than to be dependent on some random persons from the home care service, and even though we try to have permanent professionals with each citizen we will never act in the same way as a wife. (Interview with the evening assistant)

The granted home care is always allocated to the individual client, not to the household. This means that the professionals have the possibility and the right to select whom and what in the home they should relate to or consider. In the pauses that often occur between the allocated activities with the client, the professionals sometimes direct their attentions towards his wife. This is not strictly speaking a part of the work definition, but it seems inevitable because of the many hours they spend in the home and the need to relieve the mental burden of both the client and his wife:

I have a limited capacity and have told them: I am here for (the client), not for (the wife). Of course, I talk to her about recipes, weather or shopping. I do not go into her problems (Interview with the daytime assistant).

From the position of the professionals, the involvement of the client seems to be embedded in the structural condition of possibilities, which is allocating help, not to the entire household, but only to the individual client – despite the fact that the professionals are aware of the complex problems of the household – and try to act within the structural framework.

In general, the meetings with the assistants seem to be an important and temporally significant part of the everyday life of the client and his wife; they were at the house of the
The time the healthcare professionals spend with the client is measured out and allocated in relation to the services they have to carry out for the client. This means that the separate service activities are not negotiable with the assistants and the client. Only the chronological order of the activities in the given timeframe can be negotiated. The time allocated to a service is allocated as a service offer to the client; that is, the service offer can be received or rejected. The time is not allocated freely to the client, and time is bound to the individual service. As it happens, the allocated time and services set a limit to what and how much the client has at his disposal and how much influence he can have in relation to the professionals who are committed to their work:

I often think that we have a lot of power. We are the ones who run the business, we kind of have to. We aren’t there all day. We have to stick to it, that now we do this, now we do that. There is a plan, after all. I have a plan, at least. We run a tight schedule and a lot has to be done within a certain time. (The client) loves to sit in his bath. And he is more or less allowed to decide for how long time he stays there. But occasionally, I have to interrupt. But I do try to let him decide when to do what. (Interview with the daytime assistant).

The client has finished his dialysis and suddenly remembers that he has forgotten to fold swabs for his nose and starts folding them. Assistant says that he should have thought of that earlier when he was sitting getting dialysis instead of talking. There is no time for folding swabs now; he has to take his shower. (Field notes)

Seemingly, the more dependent the client is on the professionals, the lesser influence he has on his everyday life. And the more dependent the client is on the professionals, the more dependent the professionals are on doing their work tasks within the structural framework. The possibilities for involvement of the client in the help–helper relationship are related to the order of things that have to be done, according to the schedule. This indicates that client involvement from the professionals’ perspective is grounded on a structural time schedule, where the client is allowed fragmented influence on his own life. From the client’s perspective, it is a matter of involvement and influence on his whole life and every day in his life. In that way, the question of client involvement seems to be a balance of how much and how little is needed to comprise everyone’s requirements:

(I) ask him, what do you want to do first: on the loo or dialysis? Then he is given a little co-determination. But he has to do his dialysis. We have to go there. [...] Where he can decide for himself, I try to give him some options. But you can only give him limited options. [...] I also try to let him decide for himself what he wants, and in what order. [...] I’m thinking: how would you feel in this situation? How would you like people to act towards you? (Interview with the evening assistant)

In contradiction with the general tendency of the client to be the subject to the schedule of the professionals, the case study shows how the need of going to the lavatory has the capacity to overrule the schedule of the professionals and take precedence. Here, the client himself decides unrivalled. Otherwise, the client would be enrolled in an undignified and degrading situation involving bodily excretion, and the family and the professionals would subject themselves to unnecessary cleaning of both the client and the surroundings:

When I have to go to the toilet, it has to be NOW, or I will relieve myself in my trousers or in my bed. Or when I have to vomit. (Interview with the client)

The administrative norm is that the client is assigned to a bath once a week, but this can be negotiated and the needs of the client can be taken into account to the extent the administrative home-care allocator estimates it reasonable. This seems to be an estimate that depends on the persistence requirement of the client and his family. The estimation is a balance of options between pros and cons in relation to the administrative procedures, the requirements of the client and consideration of the client – and of the administrative home-care allocator:

The client and the assistant prepare the bath. The client takes off his vest, sitting on a chair in the bath. The assistant
helps him with his trousers. The client almost does the actual bathing himself. The assistant washes his hair twice and his back. The client expresses pleasure with the bath. His wife tells that the client gets a bath twice a week (as demanded by the home care: a bath once a week was considered insufficient.) The client has always been meticulous when it comes to personal care. (Field notes)

All in all, the analysis shows that both the client and the professionals are caught in the logic of the home-care system and its ways of allocating time and tasks. It defines the content of the job of the professionals, who have to document their duties and thereby are controlled by and subject to the system, with less involvement in and influence on their job situation. There seems to be very little space to negotiate the order of the tasks between the professionals and the client. However, toilet issues cancel any negotiation and, thus, any temporally and structural management. Both professionals and client seem to be limited in their possibilities and wishes for client involvement in, respectively, their professional work and an everyday life lived independently of healthcare professionals.

‘Client Involvement’ outside the home: Liberal business and mutual goal setting

Whenever the allocation of home-care services is assigned in the Danish social legislation, it is regarded as a service benefit where assignment to physiotherapy for rehabilitation is based on the physician’s referral. It is the assignment of the physiotherapist that decides the best possible treatment within the timeframe given by the collective bargaining. Actually, the client is assigned time to the physiotherapist, not to a specific treatment. This is in contrast to the public home-care service where a specific task triggers a certain time. Treatment of a more permanent nature takes place in a public home-care service where a specific task triggers a certain time. Treatment of a more permanent nature takes place in the private labour market where the physiotherapist offers a service and the client pays for it. This implies that the physiotherapist accommodates the hope by giving space of freedom for training and future dreams. This seems to happen without professional ambitious pride but with a financial benefit.

The client never walked at home during the time of these observations. Apparently, walking is an activity that is only being practised in the physiotherapy clinic. Here, the physiotherapist relates to the hope of the client, and the physiotherapist accommodates the hope by giving space of freedom for training and future dreams. This seems to happen without professional ambitious pride but with a financial benefit.

All in all, the decision-making and involvement in decisions in a liberal business seem to be a relatively equal matter between the client and the businessman, here the private physiotherapist. To a certain extent, the frame of the market in private physiotherapy seems to necessitate this equality and involvement of the client in the execution of the business, as a consequence of the possibility that the client will fail to buy the service. In that way, the physiotherapist has to do a good job, in the sense of what the client assesses to be a good job for him. In such a context, client involvement seems to be understood as customer satisfaction. The professional standards for good clinical practice are balanced with doing business. The business must go on; in that way, the client as a customer defines and decides what is important to him in his everyday life.

Converting a home to a working place: Refurnishing a life

A home is not just a home when it comes to allocation and reception of home-care services. The home may need
alterations such as removal of furniture, change in room design or instalment of devices or assistive technology, to comply with the requirements for a working place with ergonomically satisfactory conditions for the professionals. Here, the client has limited influence on his own home and its arrangements and décor if such services are required. The working conditions are prioritised higher than the client or his family’s wishes for the arrangement or décor of his home. This is simply due to a set of health and safety laws applying for the professionals. In principle, you can live under any conditions you want to, but the professionals are only allowed to work under specific conditions:

The wife tells that the client has not always been able to get a bath because of the design of the bathroom that meant bad physical working positions for the care staff. A meeting was held with both the leader of the home care service (a nurse), the occupational therapist, the physiotherapist, the client and his wife. The bath had to be refurbished if the client were to get a bath again. (Field notes)

And, at the same time, we have to respect that their home is a part of our working place. They have to be there with their things and their privacy. You are not supposed to notice that we are present but of course you do. [...] If you don’t want to remove the rugs, if you don’t want to move out, if there is a need of a hospital bed. If you insist that the wife must use a tiny toilet where there is hardly room to move. Then we try to say that it just won’t do! We quickly sense with the wife or the husband that nothing must be changed. Then we have to bring the leader (a nurse), Then they explain that the girls have to be able to work, that things have to be in this or that way. And so it is. We don’t want to break our backs with this work. (Interview with the daytime assistant)

It seems obvious that if the assistants are not able to persuade the client to meet their requirements, they bring in healthcare professionals with a higher position in the healthcare system to discipline the client and the family.

One of the dominant ideas within the healthcare service also unfolding in this case is that the client ought to be activated and motivated to activity, involved in his own self care and health promotion, despite his life being dominated by inactivity. This too may call for alterations in the home. In this case, the client’s wife stands up against some of the iterations because any physical alteration of the home is a visible sign of their abnormal situation. It is a sign of incurable illness and misery:

(The assistant): You still want to be able to paint. Whether you are right or left handed. It is mostly that hand that doesn’t work. [...] I said that of course you have to move a little around, there has to be some change in your home, you have to make up your mind about it. But (the wife) doesn’t want to. But then I ask him if he has tried to talk with (wife) about how important this is for you. No, he hasn’t. (Interview with the daytime assistant)

In this way, the client is caught between the good intentions of the professionals and the couple’s need to maintain the physical setting of the life they have lived. But the client’s own voice is faint. His influence is vague as he is dependent on both family and professionals and subject to the structural frame in his everyday life.

In several respects, the home gets institutionalised when home-care service becomes a part of the client’s everyday life. The life of the household is unfolding between the health and safety laws for the professionals and their usual way of living. This affects the client’s ability to decide what is important in his life and surroundings. He has only limited opportunity to make decisions; as a care receiver, he is subject to the same laws.

**DISCUSSION**

To choose a sociological framework means to choose a perspective for the study, while knowing that other perspectives could have been chosen. It is a way to manage and direct both the field study and the analysis. The analysis consists of detecting correlations and patterns and their various ways of manifesting themselves and is not an attempt to present evidence for the correlations’ statistical incidents or variations under different circumstances. At the same time, the analyst tries to understand and explain what is going on in practice, not to judge if it is good or bad.

In Denmark, home care is practised, administrated and managed within a neoliberal ideology whose fundamental idea is to minimise public costs and to privatise as many welfare services as possible. The same pattern is found in several countries in Europe and North America (Duncan and Reutter 2006; Bjornsdottir 2009). Generally, cash allowances remain relatively limited in the Nordic countries, where they have been used mainly to support family care. In Denmark and Sweden, cash options play a very limited role and consumer choice is facilitated by allowing choice between home-care service providers, as both private and public services are fully or partly paid by the state (Rostgaard 2011; Krøger and Leinonen 2012). Rostgaard and colleagues show that it demands resources and an overview of one’s situation to choose a private home care; therefore, most elderly choose public help in Denmark. Denmark probably differs from other Western countries in this respect (Rostgaard 2011; Rostgaard and Pfau-Effinger 2011; Rostgaard et al. 2011). However, several international studies find that healthcare professionals seem to be subject to the structural framework, and the client seems to be subject to both the structural framework and the professionals (Glasdam 2003; Oudshorn et al. 2007; Svensson et al. 2011).
Although orienting this single case study around a client who had been selected on our behalf by a Home-Care Department leader who might be regarded as part of the case may have departed from Bourdieu’s (1999) recommendation that every participant is specifically chosen on behalf of his position in the studied field, the case did surface analyses that suggest how the logic of medicine socialises and rules the home-care services as an underlining structure. There seems to be both structural and practical limitations to client involvement in practice. The results of this study show how home-care services are estimated, assigned and allocated within a time-task schedule and how this affects the possibilities of involving the client. One way the state minimises the public employees’ degree of freedom to control them can be using standards or splitting the production in parts where the individual’s influence on her or his own work is reduced (Harvey 2005). The professionals seem to involve the client where they find room for doing so and in that way they try to act humanely in a fundamentally inhuman neoliberal organisation. The results underline how the structural framework of the home care limits the possibilities for carrying out ‘client involvement’. The client’s need for home care is dissected into individual activities or services and into the amount of time these activities require. Therefore, the schedule in itself limits the involvement of the client in decisions and activities in his own everyday life, as both the individual activities and the time to perform the home-care services are predetermined for the client and the professionals alike. With Bourdieu (1999), you could say that both the professionals suffer in their job performance and the client in his everyday life, as the possibilities are embedded in the space of allocated time and the negotiation of priorities of the tasks in that space. But the point is that ‘involvement’, seen from the position of the client, is more than this. Involvement is a question of his whole life and conditions for living and is not only a question of fragmentary situations constituted of professionals and their specific allocated tasks.

Home-care services take place in the home of the client, as the term indicates. The constitution of a home-care client seems to occur when the family of the client is no longer able to manage the client’s need for care. It is a general tendency in the Western countries that families turn over care to professional institutions, for example kindergartens, hospitals and home care (Larsen 1999). The constitution legally allows formal healthcare professionals to enter the home. The professionals seem to regard the family as being an averse and lazy co-worker and purport that if the family would only pull themselves together the professional assistance would not be necessary in the home. On the other hand, the professionals describe themselves as guests, but despite this ambiguity it seems clear that the ‘healthcare agenda’ works within the wider ‘life agenda’ of the older patient within the home setting, as McGarry (2010) also points out. A home is more than a place to live. A home has symbolic functions in the way we arrange the furniture, the colours, the art works and the décor we choose to frame and narrate our lived life by. A home is a private place, usually separated from the public space. All this changes when a person receives home care. Both the professionals and the client seem to be caught between the working conditions of the professionals and the client’s way of constructing his home and life. In that way, the professionals bring the institution into the home and thus institutionalise and medicalise the home, as Gullestad (1989) and Engström (2012) also have shown. The construction of this single case is based on the client’s perspective of his relations to family and formal healthcare professionals, and therefore, the general practitioner is not included in the case. Obviously, it seems as a weakness in the study where the analyses probably could have been qualified by including this position. The analyses show precisely how the logic of medicine socialises and rules the home-care services as an underlining structure, even in the absence of the physician.

Both professionals and clients are structurally limited in their involvement when a home is turned into a working place and vice versa. Duncan and Reutter (2006) have described this as a trend towards the medicalisation of home care. ‘Client involvement’ is practised between the laws on Working Environment and the client’s wishes for his home, but the law always seems to overrule the client’s wishes for involvement and the professionals’ possibilities to involve to client. Hence, in practice, the rules and regulations of home-care rule out client involvement.

The results point to one possible transgression of the structural and practical limitations of client involvement – occurrence of bodily excretion. This occurrence in the home seems to be able to disrupt the structural framework and the order of things and open up for some sort of ‘client involvement’, in the meaning of the client’s own right to define ‘what has to happen in my life right now’. Bodily excretion is the exception that proves the rule of the supremacy of the professional schedule of home care. Turner has explained how bodily fluids challenge our sense of order and orderliness (Turner 2003). Given that the client gets help as required in relation to his needs to go to the toilet, order is maintained, and time and work are saved compared to a situation where disorder would have to be rectified. In addition, in the Western cultures, not to be able to control one’s bodily secretions is valued as among of the most humiliating situations an adult can imagine; this
also subject to the structural framework, which means the client's own way of living. The professionals themselves are of the neoliberal healthcare system seems to undermine the importance in everyday life and therefore subject to the regulations of the private life. Being dependent on practical professional assistance in one's own home and maintaining one's own day life seems to create a dilemma between being institutionalised in one's own home and maintaining one's own private life. Bodily excretions overrule the structural time schedule and task allocation of the professionals.  

In the realm of the private physiotherapeutic practice, where the client becomes a customer shopping for services in an apparently free market, client involvement seems to be enacted as a sort of co-determination to ensure customer satisfaction. It seems that the professional arguments and standards are overruled by financial marketing where maximising profit is the absolute goal in the case of private healthcare services (Skov and Kermenoglou 2001). The client is apparently given full responsibility of his own treatment and is thereby rendered a conspicuous involvement in the private healthcare service.  

Finally, the method of this case study has to be discussed a bit further below. It is a well-known and well-tested anthropological method to move into the environment and context of the studied persons, in this study a home-care setting (cf. Wulf-Andersen 2004; Kofod 2008; Thomasen 2009; Terp and Glasdam 2010). Within such a method, an ethical dilemma obviously appears as to how to intrude in a private sphere for the client and his family to accept the intrusion and how the participants individually and collectively handle the situations. The researcher was very aware of the participants' well-being and needs and adjusted her observations in relation to the actual circumstances. Both the interviews and the observations were carried through in an awareness of used language, presence and genuine interest.

CONCLUSION AND PERSPECTIVES

Home-care service is based on a neoliberal ideology, which means that efficiency, calculability, predictability and control over people are in focus when assigning and allocating help and time to help clients. The ideology in itself has limited space for involvement of the client or the professionals, because everything is standardised in advance. To the client (and his family), practical assistance of professionals in everyday life seems to create a dilemma between being institutionalised in one's own home and maintaining one's own private life. Being dependent on practical professional assistance in everyday life and therefore subject to the regulations of the neoliberal healthcare system seems to undermine the client's own way of living. The professionals themselves are also subject to the structural framework, which means the political decisions, the administrative rules and the medical logic whereby the physical body seems more important than psychological or socials needs. All in all, this gives the professionals a relatively limited space to perform their professional duties. Involvement of the client in home-care practice is restricted by the allocated time and the preferences of the professionals. The working conditions of the professionals have higher priority than everything else in the home of the client. In that way, the client is subject both to the structural framework and to the professionals. On the other hand, the client seems to be totally involved in private health care as a liberal business where satisfied, self-determining clients enhance earnings regardless of professional standards.

The results here are based on a single case, and although the theoretical analysis argues for generalisation on a higher level, the results may still be regarded as hypothetical and should be qualified and nuanced in studies consisting of several client cases. However, when analysing the concept of 'client involvement', it seems clear that client involvement means at least three things: (i) from the position of professionals in public healthcare service it means 'how to incorporate the wishes of the client in the daily work under the given, indisputable conditions'; (ii) from the position of professionals in private practice it means 'to follow the will and needs of the client to ensure and optimise business'; and (iii) from the position of the client it means 'how to define and live my own life'. All in all, involvement of clients and professionals in public home care seems to be more of a political illusion than a practical reality.

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REFERENCES


Færch J. 2008. Patient participation in a professional nursing context: A literature-based exposure of how patient participation can be comprehended and put in to nursing context, and which implications it may have to clinical nursing practice. Master’s Thesis, Aarhus University, Department of Nursing Science.


