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Patients' participation in decision-making in the medical field – 'projectification' of patients in a neoliberal framed healthcare system

Stinne Glasdam, Christine Øye, Lars Thyrsøe

ABSTRACT:

This article focuses on patients' participation in decision-making in meetings with healthcare professionals in a healthcare system, based on neoliberal regulations and ideas. Drawing on two constructed empirical cases, primarily from the perspective of patients, this article analyses and discusses the clinical practice around decision-making meetings within a Foucauldian perspective. Patients' participation in decision-making can be seen as an offshoot of respect for patient autonomy. A treatment must be chosen, when patients consult physicians. From the perspective of patients, there is a tendency that healthcare professional to supply the patients with the information that the healthcare professionals think necessary for the patient to make his/her own decision. But patients do not always want to be a 'customer' in the healthcare system; they want to be a patient, consulting an expert for help and advice, which creates resistance to the some parts of the decision-making process. Both professionals and patients are subject to the structural frame of the medical field, formed of both neoliberal framework and medical logic. The decision-making competence in relation to the choice of treatment is placed away from the professionals and seen as belonging to the patient. A 'projectification' of the patient occurs, whereby the patient becomes responsible for his choices in treatment and care and the professionals support him with knowledge, preferences, and alternative views, out of which he must make his own choices, and the responsibility for those choices now and in the future. At the same time there is a tendency towards de-professionalisation. In that light, participation of patients in decision-making can be regarded as a tacit governmentality strategy that shape the location of responsibility between individual and society, and independent patients and healthcare professionals, despite

the basically desirable, appropriate and necessary idea of involving patients in their own situations from a humanistic perspective.

Introduction

The Danish healthcare system is based on public welfare provision and decentralized welfare administration (Vrangbæk & Christiansen, 2005), as in many other Western countries.

Denmark is increasingly being influenced by marketisation principles organising healthcare (Bertelsen & Rostgaard, 2013). The entire society and thus also the healthcare system is organised as services based on neoliberal bureaucratic regulations and ideas (Mik-Meyer & Villadsen, 2007; Holen, 2011; Glasdam et al., 2013a, 2013b), that is, political ideas based on minimising public costs, privatising as many welfare services as possible, and emphasising individual freedom; especially in acting and expressing oneself freely (Harvey, 2005). A study of white papers (public health policies) in Scandinavian countries has shown that Denmark is more neoliberal than the other Scandinavian countries stressing the importance of individual behavior, responsibility and autonomy when it comes to public health policies (Vallagårda, 2007). Hence, the Danish health programme emphasises the individual's responsibility to take an active part in decisions concerning his/her health. In addition the Danish Health Act is influenced by neoliberal ideas formulating frameworks and standards to guide behaviors of professionals and inform patients to take on an active role in regards to their own healthcare (Bekendtgørelse af sundhedsloven, 2010: Chapter 5. Patients' involvement in decisions). The patients are expected to be well-informed and to be able to choose between relevant healthcare services and treatments. Danish researchers have claimed that the ideal patient is regarded as one who is responsible, strong, self-determined, controlled, and acknowledges and accepts the responsibility of playing an important part in handling his/her healthcare-related problems (Mik-Meyer & Villadsen, 2007; Holen, 2011). Similarly, researchers of neoliberal health policies in other countries underscore how the

neoliberal subject is an individual who is morally responsible for navigating the social realm using rational choice grounded in market-based principles (Rose, 2003, Evers, 2003; Harvey, 2005; Mol, 2008; Boas & Gans-Morse, 2009; Hamann, 2009).

Throughout the last 35 years, Western health policies, educational curricula and institutional health organisation have highlighted patients' active participation in decision-making in healthcare (Bovenkamp & Trappenburg, 2009; Glasdam et al., 2013a, 2013b). Accordingly, patient participation in care and treatment and related decision-making is desirable in both health politics and as part of legal rights movements in many western countries (e.g. Sahlsten et al., 2009; Omeni et al., 2014). That is, patient participation is both anchored in a democratic and humanistic ethos underscoring patients as active participants (Oeye et al., 2009), as well as anchored in a neo-liberalistic ethos underscoring patients as 'customers' (Mol, 2008; Holen, 2011; Fotaki, 2013; Powers et al., 2013). However, there is no consensus on how to interpret 'participation' (Færch & Harder, 2009; Lyttle & Ryan, 2010; Olesen, 2010; Cribb & Entwistle, 2011). Currently, there are many models of patient participation in decision-making, such as 'Shared decision making' and the 'Person-Centered Communication and Reflection Model', which aim to secure and guarantee the patient's voice in healthcare decisions (Ruland, 2005; Murray et al., 2006; Légaré et al., 2008; Zoffmann et al., 2008; Sandman, 2009; Sandman & Munthe, 2010; Sandman et al., 2012; Lenz et al., 2012). To take part in decision-making the patient must have enough information and support from professionals to be able to make her/his own decision about her/his treatment and care (Coulter et al, 2008; Bekendtgørelse af sundhedsloven, 2010).

Both in medicine and nursing, patients' participation in decision-making is articulated as a good method of involving patients in relation to their own illness and symptoms management (Ruland, 2005; Stacey et al., 2008; Zoffmann et al., 2008; Burton et al., 2010; Chewning et al., 2012). The notion is that patient participation: can led to improved care outcomes

(Stringer et al., 2008; Weiner et al., 2013), is a useful way to reduce costs in the healthcare system (Lee & Emanuel, 2013; Oshima & Emanuel, 2013; Prabhakar et al., 2014), makes the patient cope with illness in everyday life (Zoffmann et al., 2008; Thorgård, 2012), optimises management of treatment and lifestyle (Olesen, 2010; Sandman et al., 2012), and protects the patient's autonomy (Sandman, 2009; Sandman & Munthe, 2009, 2010; Sandman et al., 2012). Healthcare professionals are obligated to protect the individual's autonomy and the individual's right to self-determination and, by extension, invite patients to participate in decision-making in the healthcare system in order to meet these claims. Consequently, patients are free to decide for themselves what is going to happen in their life, even in illness and hospitalisation (Mathar, 2008). According to Danish law, no treatment, care or prevention may be initiated or continued without the patient's informed consent (Bekendtgørelse af sundhedsloven, 2010). On the one hand, this means that a patient has the right to say 'yes' or 'no' to medical treatment, physiotherapy, occupational therapy and nursing, and the idea is that through patient participation in decision-making this can be accommodated. On the other hand, respect for patient autonomy has to be balanced with knowledge of the patient's literacy and ability to understand information, both of which affect the patient's ability to give informed consent (Rossel, 1985). However, research has shown that attempts by physicians and nurses to secure patient involvement in decision-making often end up supporting the professionals' agenda based on the dominating medical model of the right choice of treatment or care (Whitney 2003; Glasdam, 2003, 2013a, 2013b; Dahlager, 2005; Oeye et al., 2009; Upton et al., 2011; Knutsen et al., 2011).

This article focuses on patients' participation in decision-making in meetings with healthcare professionals in a healthcare system, primarily from the perspective of the patients. It draws on qualitative empirical studies in two different outpatient clinics by the authors. Two exemplary cases have been selected and form the empirical basis for analysing and discussing

patients' participation in the decision-making, within a theoretical framework informed by Foucault and his concepts of power, resistance and governmentality.

The theoretical framework as analytic lens and starting point for discussion of the findings

Foucault had a critical eye for what characterises power in modern societies as a consequence of history, scientific discourses and institutions. He showed how actors in modern societies are caught in institutional structures, which pin down and form the actors' actions (Foucault, 1977; Rabinow & Rose, 2003; Rose, 1994, 2003; Mik-Meyer & Villadsen, 2007). Power is a relationship and is exercised throughout the social body, where it operates at micro levels of social relationships. Power is omnipresent and a necessary, productive and positive force in society (Foucault, 1975, 1977; Rose, 1994; Mik-Meyer & Villadsen, 2007). Power is understood as the ability to bring things into action. As such, power will always generate some kind of resistance (Foucault, 1977). The institutions, their systems and their roles as bodies of knowledge define norms of behavior and deviance, and physical bodies are subjugated and made to behave in certain ways; Foucault calls this technology 'biopower' (Hamann, 2009; Foucault, 2010). Biopower intends to achieve the subjugation of bodies and the control of populations (Foucault, 1998). It is inextricably bound up with biopolitics in the use of medical technologies and apparatuses for the care and administration of life itself (Foucault, 1984). Foucault's interest in biopower and biopolitics leads to his the concept of governmentality (Foucault, 1991), which in short means the way the self is governed through techniques of self-governing, for instance by giving individuals freedom and choices (Foucault, 1994).

In this article, the selected empirical cases were analysed and discussed through a lens of the above-mentioned Foucaudian concepts of power, resistance and governmentality. The

analysis was primarily from the perspective of the patients and focused on the meetings between healthcare professional and patients in order to illuminate patients' participation in decision-making in those meetings in the healthcare system. It means that the analysis was oriented towards patients' self-determination of treatment from the perspective of the patients. The analysis was not interested in the ideas behind the practical handled situations, but only in the situations *in actu* and the impact on patients.

Choice and presentation of cases as basis for the analysis

We have chosen two exemplary cases from previously research work. One case is about meetings between healthcare professionals and patients and their relatives in order to decide on whether to get treatment for cancer, which is also part of a randomized clinical trial (RCT). The other case is about meetings between healthcare professionals and patients when they have to decide on patient treatment in an outpatient clinical practice. This case illuminates patients' uncertainty about choosing the right treatment.

Case 1: Patients' participation in decision making about and participation in RCT

This case emerged from an interview study where the empirical material consisted of 28 interviews with physicians, nurses, patients and their relatives in an oncology ward in Denmark (Glasdam, 2003, 2007).

An RCT guided a large part of the treatment offered and given to patients in the oncology clinic.

"We are strictly brought up with those clinical protocols. There are some measurements, [based on the idea that] disease should respond [to treatment], or some measurements, disease should progress, before you stop [treatment]. And that's really the rule we live by in

the practical world. It makes our life easier sometimes [...] oncology gets out of hand if you do not have objective measures for the introduction of new drugs for tumor reduction [...] ".

(Physician)

Both physicians and nurses in the oncology clinic had an explicit awareness that the RCT approach ruled the clinical practice and made the treatment handy for physicians and nurses; they knew exactly what to do and when.

Information was considered and decisions made by a group consisting of a physician, a nurse, a patient and often a relative. During an outpatient consultation, the physician gave oral and written information about the RCT to the patient and the relative; nurse, patient and eventually relative. They all listened quietly to the one-way oral information, with the opportunity to question the physician afterwards. Questions from the patients and the relatives were often few; most patients kept quiet and were tacitly accepting the physician's point of view; others had questions such as:

"I asked if it was something they had tried before, because I certainly would not be an experimental rabbit. It was something they did often, and it was something they had good experience with [...] I wouldn't have chemotherapy, but as doctors say, well, that's all that we have, all we can offer you, so I have to revise my opinion and say yes. Well, I have not dared to refuse to receive it, because what is important for me to stay alive". (Patient)

Usually, after a week, the patient returned to the oncological clinic and replied to the offer of participation in the RCT. The information provided by the physician was both a juridical legitimation for the physician in inclusion of patients in the RCT and information, and a means of ensuring that the patient understood what the RCT and treatments options were about, although it was clear to many of those involved that the patient was not always able to comprehend all information provided (Glasdam, 2003, 2007).

“The patients complain that they have not been told [about RCT and treatment options], but it is clear from the record or patient information that they have all been told. They do not understand that there can be serious side effects, which you must tolerate if you want to be cured ”. (Physician)

“The patients and relatives pay attention to a single part of the information and do not necessarily hear the rest of it. It is understandable, because there are many things they need to grasp in a short time ”. (Nurse)

“My mother was cheated. If it was not a direct lie, at least it was uncertain because it was a trial. She could have chosen an ordinary chemotherapy if there had been someone who had recommended it, but they didn't [...] [the physician said] there were no major side effects and [...] because it was an experiment, it was even more controlled [...]. Both were certainly lies [...]. (Relative)

Nurses tried to stay ‘neutral’ in relation to the patient's consideration of participation in the RCT and referred the patient to discuss the matter with her/his relative rather than with her/him, if the patient asked her/him (Glasdam, 2003, 2007).

Case 2: Patients’ participation in decision making about best treatment

This case was constructed on empirical material from an ongoing participant observation and interview study including 15 patients with atrial fibrillation in an outpatient clinic in Denmark. A physician consulted the patients during the first meeting and a specialised nurse consulted them in the following consultations; this meant that the physician and the nurse never met together with the same patient.

A 63 year old man had been diagnosed with atrial fibrillation more than one year ago and had been treated with anticoagulation. Now, he was referred to the clinic because of a minor

stroke. During the first consultation, he underwent a medical examination with ECG and echocardiography. The physician diagnosed an unaltered atrial fibrillation, and an optimised treatment was needed. The physician informed the patient about the two kinds of anticoagulation strategies as recommended in national and international guidelines. The physician explained, in detail, pros and cons of the treatment strategies, explained his own preference and asked for the patient's preferences. The patient wanted to discuss the choice with his general practitioner (GP) before he made a decision. In fact, the GP and the physician in the outpatient clinic disagreed about choice of treatment:

“My GP and the physician at the hospital discussed which kind of medicine I should have. They were so kind listening to my thoughts about treatment choice. And then I was asked to decide which I preferred. I was lost. Then I got mad. Then I really got mad, because I was not competent to make [such a decision]. I did not find myself ready for that. It [the decision process] did not take place in a responsible manner. I was ordered to make a decision about something that I did not have the prerequisites for making [...] and thereby take the consequences if I made a wrong choice.”

Another 74 years old male patient in the same study said:

“I am not sure. Maybe I felt that he [the physician] was a bit uncertain whether it should be the medicine he preferred or if it should be the older kind of medicine. Maybe it is wrong to say he was uncertain. He was probably in doubt. It was as if he said that I could get this, but I could also get that.”

Those patients never talked with the physicians or the nurses about these feelings and experiences. The patients did not consider themselves to be qualified to be part of the decision making process and refused to take the final decision about treatment choice. From the perspective of patients, the physicians then made decisions based on their knowledge and

preferences. In subsequent consultations, the nurses took no part in the decision-making process and did not discuss the decision-making process with the patients. The nurses asked the patients how they tolerated medication side effects and how their symptoms were at that moment. The disease, symptom management and medical treatment were front of stage; in consultations with both physicians and nurses.

Analysing discussion

A treatment must be chosen

In the two empirical cases, the patients are given the choice to be treated in one or another way, whether under the regime of the RCT or in everyday clinical practice. The professional's involving of the patients in the decision-making process does not give patients the choice *not* to engage. Taken to its extreme, every healthcare decision can be defined as a situation where more than one decision is possible; the patient might decide between been treated/cared for or not being treated/cared for; and if s/he wanted to be treated/cared for there was often more than one way to go. In both *case 1 and 2* patients and professionals agreed that treatment is necessary for the patient. However, the patients and the professionals disagreed on who should make the treatment decision. The patients in *case 2* thought that it was the professionals' job to make a decision on behalf of the patient, the patients interpreted the professionals action as meaning that they had to decide treatment themselves based on background professional information; the decision-making process was unknown for them. Those two patients *in case 2* reacted with resistance to the professional order and refused to take responsibility for the decision. The patients in *case 1* were able to figure out the preferences of the professionals, accepted those preferences and thereby accepted that the RCT should chose the treatment for each and every one of them. The medical logic of

treatment as a necessity and as the medical truth (Foucault 2010) was incorporated by both healthcare professionals and patients. From a perspective of Foucault, those logics structured the conditions and set the agenda for the meetings between professionals and patients (Hamann 2009; Foucault 2010).

In *case 1* the patients were given the responsibility for choosing whether or not to accept treatment under the auspices of the RCT. If they chose the RCT, the choice of a ‘good’ or ‘bad’ treatment regime would be based on randomisation according to the RCT study protocol. In *case 2* the patients found that the professionals tried to make them responsible for the choice of treatment, but the patients resisted and preferred not to make the decision. A healthcare system, which is anchored in a neo-liberalistic framework, assumes that patients have the choice, the capacity and the obligation to exercise such choices and responsibilities (Rose, 1996). Other studies show that patients’ participation in decision-making is particularly important when decision-making is difficult for the professionals: for instance when the effect of the treatment is unsure, when individual circumstances are important factors in obtaining the benefit of treatment, when values and preferences of the patient are changing or unknown, and when decisions are based on a personal estimate (Ruland, 2005; Keating et al., 2010; Sinding et al., 2010). The emphasis on patients’ key role in the decision-making process can be regarded as a way for professionals in the healthcare system to transfer responsibility for individual problems and initiatives to the personal level (Foucault, 1991). The language of ‘participating in decision-making’ is invoked by the state, represented by the healthcare professionals and their institutions, to help to govern the patients by placing the responsibility on patients themselves. In the two empirical cases, patients did not seem to be gaining more control over their own decision-making. Instead they were being given some of the responsibility in order to help carry out the physician’s agenda (Rose, 1996, Venkatesk & Murphy, 2007; O’Connor, 2010), and thereby regarded themselves as taking the responsibility

and consequences on their shoulders; they were tacitly being forced into a role of self-leadership and governance (Foucault, 1984; Olesen, 2010). By this we do not mean that the patients are responsible for the RCT, the actual chosen treatment, or unexpected side-effects, but they are responsible for being self-determined and choosing a principle of treatment (RCT or not) as *in case 1* or a concrete treatment alternative in clinical practice as *in case 2*. By law, the physicians are responsible for all medical treatment, whether or not it is organised as an RCT. Furthermore, participating in RCT is associated with the Declaration of Helsinki and strict legislation concerning information about the study, side effects and voluntariness of participation, which in itself calls for the patient to take responsibility and make a decision on whether or not to participate (World Medical Association, 2013). The consequence seems to be that they all do exactly what they are able and have to do. As also shown in other studies (Glasdam, 2003; Dahlager, 2005; Weber et al 2007) and in both cases, from the perspective of patients there is a tendency for physicians to set and lead the agenda, with nurses tacitly supporting the physicians' agenda, , and as seen in *case 1*, to a lesser or greater extent the patient and family do what the physicians want them to do, if they are able to decode this. In *case 2* the patients accept their immediate role in the information situation, but they did not understand the premises and the basis for the decisions they are asked to take. Those patients react to varying extents with non-articulated resistance and would have preferred not to participate in the decision about their own treatment. In that light, the patients' participation in decision-making about their own treatment in the healthcare system governs the mentalities of both healthcare professionals, patients and their families. It produces the reality and interventions in the healthcare system based on self-governing techniques (Foucault, 1991). If the patients do not accept or understand the full set-up for participating in this decision-making as seen in *case 2*, the physicians and nurses also show resistance to involving the patient in decision-making and seem to neglect the decision-making process. Instead,

according to the patients, the professionals take over, make the decisions and thereby support the medical logic concerning necessary treatment. The patients' choice is limited to those options they can understand and that are viewed as acceptable by the professionals. Basically the patients want to make the 'right choice' so as not to be blamed for not taking care of and protecting themselves against their diseases. Thereby, the patients seem to be positioned in governmental discourses as an active rather than passive subject of governance, in charge of their own well-being and self-improvement (Vahabi & Gastaldo, 2003).

When treatment becomes synonymous with experiment

Case 1 shows that oncological treatment is frequently provided using the concept of RCT.

There is a unique perception among both physicians and nurses in the oncological clinic that the RCTs are essential to treat actual patients, and at the same time, to find the most appropriate treatment for various cancer diseases in the future (Glasdam 2003, 2007).

However, for the patient it is only a question of his/her own treatment and the possibilities for a cure. In this view, the RCT functions are seen as synonymous with treatment and as instruments for quality assurance for what the physicians define as cancer treatment on equal terms with other treatment in the healthcare system. This can be regarded as a more logical way of thinking for professionals in the oncological field than, for instance, professionals in the surgical field, where treatment to cure is more prominent (Glasdam, 2003, 2007). Taken to its extreme, when only a few real oncological treatment opportunities exist, treatment is understood to mean participation in an RCT, which *per se* demands full acceptance of the decision by the patient (World Health Organization, 2013). If the patient takes the responsibility and accepts entrance into the RCT the professionals, the patients, and their families are free of responsibility for the choice of treatment; the RCT makes the treatment choice decision. In this way, the RCT is an underlying structuring tool that frames the logic of

the medical field and thereby disciplines the professionals and the patients in this field and in their practices. The RCT guides the information from professional to patients about treatment/trial, guides the role of the participants in the information session, the choice of treatment and the rules for continuing or stopping treatment (Glasdam, 2003).

In *case 2* the patients experienced the treatment as an experiment again, but not through the concept of RCT; more through the concept of the patients' own experiment in choosing their own treatment based on a large amount of medical information in an overwhelming consultation situation. The patients reacted with more or less non-articulated resistance to the decision-making process, but ended up pushing the decision back to the physicians. Since the medical clinic aims to diagnose and treat diseases, if the patients meet the ideological self-decision-making process with resistance the physicians have to take action, and have to decide treatment; this is the rule of the game that keeps the medical clinic going forward. Accordingly, the patients resisted the attempts to make them take responsibility for the choice of treatment (Foucault, 1977).

Two different interests in disease and treatment are at play

Both *case 1 and 2* show that the patients are ill and consult medical experts in the healthcare system in order to be helped, but it is not easy to understand and cope with the amount of information from the physician to the patient (and eventually family). In general, the patients want to be helped, treated and/or cared for. Apparently, the physicians and the nurses want to help, but are subject to both the structural frame of organisation of information meetings, made up of, for example, time, ideas about the right way to inform and involve patients in these meetings, agreements with the medical industry *etcetera*. From the perspective of healthcare professionals, the articulations of patients' participation in decision-making in the healthcare system is useful, good and equalises power relations between healthcare

professionals and patients (Færch & Harder, 2009; Lyttle & Ryan, 2010; Olesen, 2010; Cribb & Entwistle, 2011). However, it seems difficult for the healthcare professionals to provide information in ways that allow patients to be able to make a decision, if they so want. Physicians/nurses can provide such information in a way that obscures the treatment possibilities and confuses the patient. As shown, the meeting situations around the patients' participation in decision-making can also be regarded as an asymmetric power relation, regarded from the perspective of the patients. This means that although professional and political intentions are to equalize power relationships, the concrete actions which result from meetings between healthcare professionals and patients have an inherently imbalanced power structure which is reinforced by these meetings. By extension, Holen and Arhenkiel (2013) and Glasdam et al. (2013a, 2013b) show how neo-liberal discourses have the effect of narrowing the space for patient involvement in clinical practice. Apparently, the physicians and the nurses share their knowledge as best as they can and try to appear confident and persuasive when giving the information, but the information is difficult to understand for the patients within a tight consultation schedule. Other studies have also shown that the patients have difficulties in understanding the physicians' information about participating in RCTs (Scocozza 1994; Olsen, 2001; Keusch et al, 2014). In *case 1* the physicians' information about participating in RCT indirectly enhanced a pressure on patients to accept participation in the RCTs. Taken to its extreme, the physician provided information and communicated the experiment results as if it has real curative effects. Secondly, the physician needed to explain side effects based on European Standards and not according to patients' experience of the side effects. Thirdly, in order to convince a patient that treatment was necessary the physician cannot communicate about eventual placebo results (Glasdam, 2003, 2007; Radley & Payne, 2009). This means that the physician – and the nurse - do not share *all* their knowledge about the RCT and the consequences for the patient as a basis for making a 'good' self-decision

despite existing laws and ethical guidelines; on the contrary the physician's preference is evident and his/her powers of persuasion seem great. More than the patient's treatment is at stake. The physicians' research merit is also at stake. The notion of providing neutral information to patients is an illusion, and there can be visible and hidden interests and personal preferences behind specific information given to another. There might be a hidden interest in the professionals' research merits and commitments with the medical industry (Götzsche, 2013; Wadmann, 2014). Moreover, there might be a personal preference for some medical products which are subject to career possibilities in the healthcare system or in the medical industry (Sah & Fugh-Berman, 2013; Sismondo, 2013). This means that the physicians and the patients are not only subject to the structural frame of the healthcare system and the medical logic of treatment as a necessity; they are also subject to the medical industry that runs the RCT and makes the pharmaceutical products (Götzsche, 2013).

From the perspective of the patients, the nurses do not contribute their knowledge and preferences in order to help the patient to a decision (*case 1* and *2*). As seen in these cases, nurses support the physicians and their practice through assisting the patient and the physicians with medical issues around results of the patients' (or the physicians') decisions of treatment. There is a tendency that the decision-making competence in the choice of treatment is moving from the professionals to the patient and relatives (Glasdam 2003). Clearly, this is not a deliberate reluctance to make decisions about treatment choices on the part of the professionals, but a result of the idea of giving the patient a free choice in a neoliberal healthcare system. This practice is contingent upon an experimental practice rather than a treatment and caring practice (Glasdam, 2003, 2007).

A neoliberal conversion of a patient into a customer and declining expert knowledge

In both *case 1 and 2* the physicians unfold their expert knowledge by sharing their information and preferences with the patients, but they retreat in the decision phase and to varying extents leave the responsibility more or less to the patients themselves. In that way, the physicians provide the expert basis for the decision, but the decision itself is based on the patient, their preferences and judgment. In a way, patients are treated as 'customers' in these meetings in the clinic even though some patients do not want to 'shop' and do not have the basis to do so (Mol, 2008; Fotaki, 2013; Powers et al., 2013). Other studies show that patients are expected to search, demand and negotiate the treatment and care they want, seek second opinions, try treatments, reject them and try others, have rights and so on (McLaughlin, 2007; Olesen, 2010). In the healthcare system based on neo-liberal ideas patients can be treated as 'customers' by the professional choosing between different offers (Mol 2008; Powers et al., 2013; Fotaki, 2013). A patient treated as a 'customer' is a patient, who is able to rationally access services through the market, 'buying' healthcare in an efficient way to meet their own needs (Mol, 2008). A rational individual should be able to make a choice in full awareness of the relevant facts and features of their situation and after a careful analysis of the consequences of each of the choices, select the one which is most likely to serve their best interests (Rawls, 1983). However, as shown in both cases, patients are in a serious life situation and are not always capable of making rational choices about their own treatment. In addition, professionals might overlook the reluctance of some patients to be a 'customer' in the healthcare system. Some patients want to be a patient, consulting an expert for help and advice as seen in both *case 1 and 2*, and consequently run the risk of being regarded as 'difficult' patients who do not want to take responsibility for own treatment and health (Pii & Villadsen, 2013). In contrast, other studies show that the patients whom the professionals experience as self-responsible, active, better-knowing, critical and demanding are categorized as 'difficult' (Glasdam, 2003; Michaelsen, 2011; Fiester 2012). Unconsciously and unnoticed

the professionals convert their expert status to a 'salesman' status when they transfer responsibility for a treatment decision to the layman. In this way, the healthcare professionals get a patient who is an 'expert by experience', which is suggestive of a relationship of equals. The professional's expertise has been accrued through their training and practice and the patient's through their experience and expertise. This suggests that the healthcare professionals need to acknowledge and affirm the expertise of the other, 'the expert by experience', in assessing and agreeing a way forward (McLaughlin, 2009). Consequently, the practicalities of patients' participation in decision-making on treatment choice in the healthcare system is in danger of becoming a tool to de-professionalise the healthcare disciplines, where the professional over-rides their own professional expertise and responsibility in the name of the 'customers'' free choice to choose what will be the best for her/him. McLaughlin (2009) expresses it as the 'customer is king' and hence always right. Taken to its extreme, such 'decision-making procedure' organised by professionals in an institution ruled by neoliberalism removes expert knowledge and the current best expert knowledge in the healthcare system; it requires the patient to be an expert on choosing her/his own treatment. It can also be regarded in the light of the 'projectification' of human beings in modern society. The patient becomes project leader of his own disease and treatment. The professionals support her/him with knowledge, preferences, disagreement, and using this as background, s/he must make his/her own choices, and furthermore take responsibility for those choices and the consequences now and in the future. The only question that the professionals do not put to the patient is whether one of the suggested treatments is needed or not. This means that the patient is a lonely project leader for his/her own life and health, while the professionals – more or less invisible, quiet and secure - lead the body in the right way, ruled by the logic of the medical field. That is what Foucault called 'governmentality' (Foucault, 1991; Hamann, 2009), where the healthcare professionals indirectly rule the

actions of the human being. Participation of patients in decision-making processes can be regarded as a tacit governmentality strategy that shapes the medical field through responsible and independent patients and healthcare professionals, despite the basically desirable, appropriate and necessary idea of involving patients in their own situations from a humanistic perspective.

Finally, the analysis and discussion in this article have focused on the complexity of the situations in the exemplary cases and continuously discussed in a broader socio-philosophical perspective, primary guided by a neoliberal philosophy and its consequences for patients' participation in decision-making in the healthcare system. These choices of perspectives for the analysis and the discussion were made in the knowledge that other perspectives could have been chosen, where other findings might have been made and other discussions might have arisen. This means that this article provides one specific, transparent view of this issue, in the knowledge that it does not represent the truth, but can be considered as one of many truths. There are many answers, and there are many 'truths', depending on the perspective from which the issue is considered.

Conclusion

Patients' participation in decision-making on the choice of their own treatment in the medical field can be seen as an offshoot of respect for the patient's autonomy, which aims to ensure that all patients are free to decide for themselves what is going to happen in their life, even in illness, treatment and hospitalisation. Patients' participation in decision-making must be regarded as a product of an historic time when the healthcare system was ruled by a neoliberal framework that tended to expect patients to be well-informed and able to choose relevant healthcare services and treatment as if they were in a consumer market place, supported by

information on options from healthcare professionals. From the perspective of patients, there is a tendency for the healthcare professional to supply the patients with the information that the healthcare professionals think necessary for the patient to make his/her own decision; in this view, the healthcare professional is free of responsibility when the information is delivered. Patients do not always want to be a 'customer' or an 'expert' in the healthcare system; they want to be a patient, consulting an expert for help and advice, which causes resistance in some parts of the decision-making process. Both professionals and patients are subject to the structural frame in the medical field, formed of both the neoliberal framework and the medical logic. This means that when patients offer resistance in the decision-making process they can be seen as refusing to take responsibility for their medical decision, which the physicians then decide according to the rules of the game and thereby enables the medical clinic to proceed. From the perspective of patients, the decision-making competence in relation to the choice of treatment, whether or not within the concept of RCT, is placed away from the professionals and with the patient. There is a 'projectification' of the patient, where the patient becomes responsible for her/his choices in treatment and care and the professionals support her/him with knowledge, preferences, and alternative views, from which s/he must make her/his own choices and furthermore take the responsibility for those choices now and in the future. At the same time, there is a tendency towards de-professionalisation. In that light, participation of patients in decision-making processes can be regarded as a tacit governmentality strategy. Even though patient participation also is anchored in a democratic and humanistic ethos underscoring patients as active participants, this study shows that a basic neo-liberalistic ethos forms the relations between healthcare professionals and patient in the selected cases. This article calls for more qualitative participant observation studies to explore how such governmentality strategies work on the spot in decision-making situations between healthcare professionals and patients.

References:

Bertelsen, T.M. & Rostgaard, T. (2013) Marketisation in eldercare in Denmark: free choice and the quest for quality and efficiency. In G. Megaher & M. Szebehely (eds). Marketisation in Nordic eldercare: a research report on legislation, oversight, extent and consequences, Stockholm: Stockholm University.

Bekendtgørelse af sundhedsloven [Consolidation Act on Health Care] no. 913 af 13/07/2010

Boas TC, Gans-Morse J 2009 Neoliberalism: From new liberal philosophy to anti-liberal slogan. *Studies in Comparative International Development* , **44**, 137–161.

Bovenkamp H.Mvd., Trappenburg M.J. (2009). Reconsidering patient participation in guideline development. *Health Care Analysis*, **17**,198–216.

Burton, D., Blundell N., Jones M., Fraser A., Elwyn G. (2010). "Shared decision-making in cardiology: do patients want it and do doctors provide it?" *Patient Educ Couns*, **80**(2), 173-179.

Chewning B., Bylund, C.L., Shah B., Arora N.K., Gueguen J.A., Makoul G. (2012). Patient preferences for shared decision: A systematic review. *Patient Education and Counseling*. **86**, 9-18

Coulter, A., Parsons, S. & Askham, J.(2008). *Where are the patients in decision-making about their own care?* Copenhagen: World Health Organization and World Health Organization, on behalf of the European Observatory on Health Systems and Policies.

[http://www.who.int/management/general/decisionmaking/WhereArePatientsinDecisionMakin
g.pdf](http://www.who.int/management/general/decisionmaking/WhereArePatientsinDecisionMakin
g.pdf) (accessed on 01.02.2015)

Cribb A., Entwistle V.A. 2011. Shared decision making: trade-offs between narrower and broader conceptions. *Health Expectations*, **14**, 210–219 doi: 10.1111/j.1369-7625.2011.00694.x

Dahlager L. (2005). *I samtalens rum. En magtanalyse med afsæt i den livsstilsrelaterede forebyggelsessamtale* [In the conversation room. A power analysis on the basis of the lifestyle-related prevention conversation]. PhD Thesis, Copenhagen University, Denmark.

Evers A. (2003) Current strands in debating user involvement in social services. Giessen: Justus-Liebig-Universität. Discussion Paper for the Group of Specialists on User Involvement in Social Services (CS-US) – Council of Europe. September 2003.

Fiester A. (2012). The “difficult” patient reconceived: An expanded moral mandate for clinical ethics. *The American Journal of Bioethics*, **12**(5), 2–7.

Fotaki M. (2013). Is patient choice the future of health care systems? *International Journal of Health Policy and Management*, **1**(2), 121-123.

Foucault M. (1975) *The Birth of the Clinic: An Archaeology of Medical Perception*. A. M. Sheridan Smith; New York

Foucault M. (1977) *Discipline and Punish: The Birth of the Prison*. Penguin; London

Foucault M. (1984). Right of death and power over life. In P. Rabinow (ed), *The Foucault reader*, pp 258–272. New York. Pantheon Books.

Foucault M. (1991) ”Governmentality”. In: *The Foucault effect*. (eds G. Burchell & C. Gordon & P. Miller) pp. 87-104. Chicago: The University of Chicago Press

Foucault, M. (1994). The ethics of the concern of the self as a practice of freedom. In P. Rabinow (ed.) *Ethics. Essential works of Foucault 1954-1984*, vol. 1, pp. 281-301. London. Penguin books.

Foucault, M. (1998). *The History of Sexuality. Vol. 1: The Will of Knowledge*. London Penguin.

Foucault, M. (2010) *The Birth of Biopolitics: Lectures At The College De France, 1978--1979*. New York; Picador

Færch J., Harder I. (2009). Medinddragelse i egen pleje og behandling [Involvement in own care and treatment]. *Sygeplejersken*, **17**, 54–9.

Glasdam S. (2003). *Inklusion og eksklusion af kræftpatienters pårørende i en onkologisk klinik*. [Inclusion and exclusion of relatives to cancer patients in an oncological clinic] PhD.Thesis, University of Copenhagen. Viborg, Forlaget PUC.

Glasdam S. (2007). Klinisk kontrolleret forsøg som styrende for en onkologisk medicinsk habitus [RCT as governing oncological, medical habitus]. In: *Med Bourdieu i empirien – eksempler på praktisk empirisk arbejde* [With Bourdieu in the empirical field - examples of practical empirical work] (eds J.A. Hansen & P. Koudahl) pp. 117-130. Hexis Forum for samfundsvidenskabelig forskning. Copenhagen, Forlaget Hexis.

Glasdam S., Henriksen N., Kjær L., Præstegaard J. (2013a). Involvement of the Client in Home Care Practice– a relational sociological perspective. *Nursing Inquiry*, **20**(4), 329–340.

Glasdam S., Præstegaard J., Henriksen, N. (2013b). Placed in home care: Living an everyday life restricted by dependence and monitoring. *Nordic Journal of Social Research*, **4**, 83-89.

Götzsche P.C.(2013). *Dødelig medicin og organiseret kriminalitet. Hvordan medicinalindustrien har korrumpet sundhedssystemet* [Lethal drugs and organized crime. How the pharmaceutical industry has corrupted the healthcare system]. Copenhagen, Nyt Nordisk Forlag Arnold Busck..

Hamann T.H. (2009) Neoliberalism, Governmentality, and Ethics. *Foucault Studies*, **6**,37-59,

Harvey D. (2005) A brief history of neoliberalism. New York: Oxford University Press.

Holen M. (2011) Medinddragelse og lighed - en god idé?: en analyse af patienttilblivelser i det moderne hospital. [Involvement and equality – a good idea? An analysis of patient creation in the modern hospital]. PhD. thesis, Roskilde University, Denmark.

Holen M. and Arhenkiel A. (2011). 'After all, you should rather want to be at home': Responsibility as a means to patient involvement in the Danish health system. *Journal of Social Work Practice*; **25**(3), 297-310.

Keusch F., Rao R., Chang L., Lepkowski J., Reddy P., Choi S.W. (2014) Participation in clinical research: perspectives of adult patients and parents of pediatric patients undergoing hematopoietic stem cell transplantation. , Jun 24. doi: 10.1016/j.bbmt.2014.06.020.

Keating, N. L., Landrum, M.B., Neeraj, K. A., Malin, J. L., Ganz, P.A., Van Ryn, M., & Weeks, J. C. (2010). Cancer Patient's role in treatment decisions: Do characteristics of the decision influence roles? *Journal of Clinical Oncology*, **28**, 4364-4370.

Knutsen I.R., Terragni L., Foss C. (2011) Morbidly obese patients and lifestyle change: constructing ethical selves. *Nurs Inq.*, **18**(4), 348-58. doi: 10.1111/j.1440-1800.2011.00538.x.

Lee E.O., Emanuel E.J. (2013) Shared Decision Making to Improve care and reduce costs. *The New England Journal of Medicine*, **368**(1), 6-8.

Légaré F., Ratté S., Gravel K., Graham I.D. (2008) Barriers and facilitators to implementing shared decision-making in clinical practice: update of a systematic review of health professionals' perceptions. *Patient Educ Couns*, **73**(3):, 526-535.

Lenz M., Buhse S., Kasper J., Kupfer R., Richter T., Mühlhauser I. (2012) Decision Aids for Patients. *Dtsch Arztebl Int*, **109**(22-23), 401-8; DOI: 10.3238/arztebl.2012.0401.

Lyttle D.J., Ryan A. (2010) Factors influencing older patients' participation in care: A review of the literature. *International Journal of Older People Nursing*, **5**, 274–282.

Mathar H. (2008) When patients reject nursing care. *Sygeplejersken*, **4**, 40-4.

McLaughlin H. (2009) What's in a Name: 'Client', 'Patient', 'Customer', 'Consumer'. 'Expert by Experience', 'Service User'- What's Next? *British Journal of Social Work*, **39**, 1101–1117.

Michaelsen JJ (2012). Emotional distance to so-called difficult patient. *Scand J Caring Sci*, **26**, 90–97.

Mik-Meyer N, Villadsen K. (2007) *Magtens former. Sociologiske perspektiver på statens møde med borgeren*. [The forms of power. Sociological perspectives on the meeting between state and citizen]. Copenhagen: Hans Reitzels Forlag.

Mol A. (2008). *The logic of care. Health and the problem of patient choice*. London: Routledge

Murray E., Charles C., Gafni A. (2006) Shared decision-making in primary care: tailoring the Charles et al. model to fit the context of general practice. *Patient Educ Couns*, **62**(2), 205-211.

O'Connor C.D. (2010) Empowered communities or self-governing citizens? (Re)examining social control within the move toward community. *Social Control: Informal, Legal and Medical Sociology of Crime, Law and Deviance*, **15**,129 – 148.

Oeye, C., Bjelland, A.K., Skorpen, A., Anderssen, N. (2009). User participation when using milieu therapy in a psychiatric hospital in Norway – a mission impossible? *Nursing Inquiry*, **16**(4), 287-296.

Olesen F. (2010) Den forstærkede patient: Om patientbegreber og empowerment [The enhanced patient: About patient concepts and empowerment]. In: *Viden, virkning og virke: Forslag til forståelser i sundhedspraksis* [Knowledge, effect and action: Proposal for understandings of health practices] (eds U J. Jensen & M. Nissen & K. Thorgaard). pp307-332. Copenhagen:Roskilde Universitetsforlag, Denmark.

Olsen P.R. (2001) At være forsøgsdeltager. En kvalitativ undersøgelse af kræftpatienters oplevelse af at deltage i et kontrolleret klinisk forsøg [Being a trial participant. A qualitative study of cancer patients' experience of participating in a randomised controlled trial]. Master thesis. Aarhus: Faculty of Medicine, Aarhus University, Denmark

Omeni E., Barnes M., MacDonald D., Crawford M. & Rose D. (2014). Service user involvement: impact and participation: a survey of service users and staff perspectives. *BMC Health Services Research*, **14**,191

Oshima L.E., Emanuel E.J. (2013) Shared decision making to improve care and reduce costs. *N Engl J Med*, **368**(1), 6–8.

Pii K.H., Villadsen K.(2013). Protect the patient from whom? When patients contest governmentality and seek more expert guidance. *Social Theory & Health*, **11**(1), 19-39.

Powers B.W., Navathe A.S., Aung K-K., Jaim, S.H. (2013). Patients as customers_ Applying service industry lessons to health care. *Healthcare*, **1**, 59-60.

Prabhakar A.M., Harvey H.B., Platt J.T., Brink J.A., Oklu R. (2014) Engaging our patients: shared decision making and interventional radiology. *Radiology*, **272**(1), 9-11. doi: 10.1148/radiol.14131909.

Rabinow P. & Rose N. (eds) (2003) Introduction: Foucault today. In: *The essential Foucault: selections from the essential works of Foucault 1954-1984*. pp. vii-xxxv. New York: The New Press.

Radley A., Payne S. (2009) A sociological commentary on the refusal of treatment by patients with cancer. *Mortality*, **14**(4), 309-324.

Rawls J. (1983). *A Theory of Justice*. Oxford: Oxford University Press.

Rose N. (1994) Medicine, history and the present. In: *Reassessing Foucault: Power, medicine and the body*. (eds C. Jones & R. Porter) pp. 48-72. London: Routledge:

Rose N. (1996) The death of the social? Re-figuring the territory of government. *Economic & Society*, **25**(3), 327-356.

Rose N. (2003) At regere friheden – en analyse af politisk magt i avanceret liberale demokratier [To rule freedom – an analysis of political power in advanced liberal

- democracies]. In: *Perspektiv, magt og styring - Luhmann og Foucault til diskussion* [Perspective, power and regulation – discussing Luhmann and Foucault] (eds C. Borch & L.T. Larsen). pp. 180-200. Copenhagen: Hans Reitzels Forlag. Denmark
- Rossel P. (1985) Det informerede samtykke [The informed consent]. In: *Medicinsk etik* [Medical ethics] (eds D. Andersen & D. Mabeck & P. Riis) pp. 252-262. Danmark. FADLs Forlag. Denmark.
- Ruland C.M. (2005). Shared decision making and nursing informatics research in Norway. *Appl Nurs Res*, **18**(2): 70-73.
- Sah S., Fugh-Berman A. (2013). Physicians under the influence: social psychology and industry marketing strategies. *Journal of Law, Medicine & Ethics*, Fall, 665-672.
- Sahlsten M, J.M., Larsson I.E., Sjöström S., Plos K.A.E. (2009). Nurse strategies for optimizing patient participation in nursing care, *Scandinavian Journal of Caring Sciences*, **23**, 490-497.
- Sandman L. (2009). The Concept of Negotiation in Shared Decision Making. *Health Care Anal*, **17**, 236–243 DOI 10.1007/s10728-008-0103-y.
- Sandman L., Munthe C. (2009) Shared decision-making and patient autonomy. *Theor Med Bioeth*, **30**, 289–310 DOI 10.1007/s11017-009-9114-4.
- Sandman L., Munthe C. (2010) Shared Decision Making, Paternalism and Patient Choice. *Health Care Anal*, **18**, 60–84 DOI 10.1007/s10728-008-0108-6.
- Sandman L., Granger B.B., Ekman I., Munthe C. (2012) Adherence, shared decision-making and patient autonomy. *Med Health Care and Philos*, **15**, 115–127 DOI 10.1007/s11019-011-9336-x.

Scocozza L. (1994) *Forskning for livet* [Research for the life]. Akademisk Forlag A/S, København, Denmark.

Sinding C., Hudak P., Wiernikowski J., Aronso J., Miller P., Gould J., Fitzpatrick-Lewis D. (2010). "I like to be an informed person but..." negotiating responsibility for treatment decision in cancer care. *Social Science & Medicine*, **71**, 1094-1101.

Sismondo S. (2013). Key opinion leaders and the corruption of medical knowledge: What the Sunshine Act will and won't cast light on. *Journal of Law, Medicine & Ethics*, Fall, 635-643.

Stacey D., Murray M., Légaré F., Sandy D., Oconner A. (2008) Decision coaching to support shared decision making: a framework, evidence, and implications for nursing practice, education, and policy. *Worldviews Evidence Based Nursing*, **5**(1), 25-35.

Stringer B., Van Meijel B., De Vree W., Van Der Bijl J. (2008) User involvement in mental health care: the role of nurses. A literature review. *Journal of Psychiatric and Mental Health Nursing*, **15**, 678–683.

Thorgård K. (2012) Patientinddragelse mellem ekspertviden og hverdagserfaring [Patient involvement between expert knowledge and everyday life experience]. *Nordisk Sygeplejeforskning*, **2**(2), 96-108.

Upton J., Fletcher M., Madoc-Sutton H., Sheikh A., Caress A.L., Walker S. (2011) Shared decision making or paternalism in nursing consultations? A qualitative study of primary care asthma nurses' views on sharing decisions with patients regarding inhaler device selection. *Health Expectation*, **14**(4), 374-382.

Vahabi M., Gastaldo D. (2003) Rational choice(s)? Rethinking decision-making on breast cancer risk and screening mammography. *Nursing Inquiry*, **10**, 245 – 256.

Vallgård, S. (2007) Public health policies: A Scandinavian model? *Scandinavian Journal of Public Health*, **35**, 205-211.

Venkatesk S.A., Murphy A.K. (2007) Policing ourselves: Law and order in the American ghetto. In: *Youth, globalization, and the law* (eds S.A. Venkatesk & R Kassimir) pp124-157. Standford, CA: Standford University Press.

Vrangbæk K., Christiansen T. (2005). Health policy in Denmark: Leaving the decentralized welfare path? *Journal of Health Politics*, **30**(1-2), 29-52.

Wadmann S. (2014). Physician-industry collaboration: Conflicts of interest and the imputation of motive. *Social Studies of Science*, **44**(4), 531-554.

Weber H., Stöckli M., Nübling M., Langewitz W.A. (2007). Communication during ward rounds in internal medicine. An analysis of patient-nurse-physician interactions using RIAS. *Patient Educ Couns* ,**67**(3), 343-8.

Weiner S.J., Schwartz A., Sharma G., Binns-Calvey A., Ashley N., Brendan K., Dayal A, Patel S., Weaver F.M., Harris I. (2013) Patient-Centred Decision Making and Health Care Outcomes. An Observational Study. *Annals of International Medicine*, **158**(8), 573-580.

Whitney S.N. (2003). A New Model of Medical Decisions: Exploring the Limits of Shared Decision Making. *Medical Decision Making*, **23**(4), 275-280.

World Medical Association. (2013). *Declaration of Helsinki*.

<http://www.wma.net/en/30publications/10policies/b3/index.html> (accessed 6th February 2015)

Zoffmann V., Harder I., Kirkevold M. (2008) A Person-Centered Communication and Reflection Model: Sharing Decision-making in Chronic Care. *Qual Health Res*, **18**(5), 670-685.