Designing For Democracy: Using Design Activism to Re-negotiate the Roles and Rights for Patients

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Abstract

In this paper we focus on ‘patient-democracy’ and ‘shared decision-making’ seen from the perspective of design practice and design research. In the research on democracy in healthcare it is rarely questioned what forms of democracy underlies these concepts. We have examined three different theories of democracy and the democratic practices that belong to each of these.

For designers working to increase patient democracy it is of vital importance to be able to distinguish different structures underlying democratic practices and to work out methods for prototyping democracy. In design research there are already a number of approaches available which in one way or the other address the relationship between design, democracy and power.

We provide an account of participatory design, adversarial design and design activism thereby pointing towards design’s potential for re-distributing power and authority in healthcare. Positioning ourselves within design activism, we have set up a series of disruptive design experiments at a Danish Hospital. The aim of these experiments is to make inquiries into the hospital’s own conception of democracy and to use design activism to re-negotiate the roles and rights for patients thereby exploring various disruptive realities wherein the patient becomes a citizen with democratic rights.

Keywords

Design activism, democracy, shared decision-making

Introduction

The welfare state has been forced to re-evaluate the design and management of the services that it provides to the public, due to changes in demography (ageing), a decline in its labour force (and hence tax income) and the economical and financial crises (cf. Fotaki, 2009; Martin & Webb, 2009; Saltman, 1994). Over the years, various models have been tried out with erratic luck and success. Public services have been conceptualized according to models of efficiency in management and workflow from the late 1970s and onwards. More recently, models of consumerism inspired by Neoliberal ideologies and New Public Management and models of democracy and citizenry have flourished into the debate. With each of these models follows hidden politically motivated power structures, roles and rights for people who receive public services, and which is particularly important for designers to keep an eye on when working in this area. Not least, because the

discourse among public managers and policy-makers is too often fraught with internal contradictions and inconsistencies when it comes to the understanding of key concepts.

In this paper we focus on ‘patient-democracy’ and ‘shared decision-making’, which serve as centrepieces in an on-going attempt to reform cancer treatment within the Danish healthcare sector. This turn to democracy as a model for patient treatment is both timely and necessary, as it seems capable of moving beyond the inherent limitations of the consumerist model, which have influenced healthcare government and management for over a decade. The consumerist model is based on the assumption that hospitals will progressively improve their effective performance if they are forced to compete with each other on “market conditions”. Accordingly, treatment is looked upon as products and commodities and patients as rational consumers choosing the hospital with the shortest waiting lists, best operations, and so on. But as recent studies have documented such a model is problematic for several reasons.

First of all, while the consumerist approach to healthcare may be relevant for simple and relatively insignificant choices where easy available alternatives exist (choosing another hospital with a shorter waiting list), it fails to work in cases of life threatening deceases which require continuous care and complex procedures (Fotaki, 2009, p. 90). Secondly, case studies have revealed that the consumerist model is in fact not leading to improved effectiveness (Fotaki, 2009, p. 88). Thirdly, consumerist models are socially exclusive as they tend to disadvantage the less affluent and articulate, who do not have sufficient and accurate information to act upon. Yet, patients prefer to be treated as citizens rather than as consumers (Martin & Webb, 2009, p. 124). Finally, consumerism is to the benefit and empowering of management and budgets, not public engagement and participation.

“Patient choice”, “shared decision-making”, “patient involvement”, and “patient empowerment” are generally believed to offer a way out of these dilemmas. However, in the discourse and research on democracy in healthcare it is rarely questioned what forms of democracy underlies these concepts. Democracy may take various forms. More precisely at least three forms can be distinguished (Meijer, 2011). Some of them are compatible with the practices, culture and political structures of healthcare institutions – others are not! To shed light on these questions, we start out in this paper to examine different theories of democracy. In so doing, we aim to increase understanding of our two key concepts: patient democracy and shared decision-making.

In the following section, we move on to discuss how designers and design researchers have worked out methods and practices for creating enhanced democratic conditions for people. In particular, we will focus on recent developments in participatory design (Björgvinsson, Ehn, & Hillgren, 2010), adversarial design (DiSalvo, 2012) and design activism (Markussen, 2013). Positioning ourselves within design activism, we have set up a series of disruptive design experiments at the Oncological Department at a Danish Hospital. The aim of these experiments was twofold: i) to use subversive tactics as a method to make inquiries into the hospital’s own conception of democracy and how it is manifest in their practice of patient democracy and shared decision making; ii) to use design activism to re-negotiate the roles and rights for cancer patients thereby exploring various disruptive realities wherein the patient becomes a citizen with democratic rights. These experiments and the conclusions that can be drawn from them are discussed in the remaining part of the paper.

Three forms of democracy

The term ‘democracy’ is usually translated from its Greek origin as the “rule and power of the people”. But “the rule and power of the people” can take many forms and may be motivated by different political ideologies and agendas. What some conceives to be democratic, others may deem blunt capitalistic, socialistic or technocratic. In the public debate of whether democracy is a

tenable model for the healthcare sector, it is rarely asked what form of politics and democracy are at stake. The same lack of clarification is dominating design research and design thinking. Design researchers often talk about democratizing innovation and design as being political, but fail to articulate what one should understand by democracy and the political. If the general aim is to reform healthcare services according to models of democracy, and to use design for this obvious political purpose, then it would be a relevant starting point to specify what forms of democracy one could possibly design for.

In sociology and political philosophy, it is a commonly held view that we entered the "democratic age" with the American and the French revolution as the most important historical events. Even though Plato speculated on Athens being the first democracy, the Greek city state was in fact, as Rancière (2010) has eloquently argued, truly an aristocracy: rule of an elite with women and slaves being excluded from political participation. The modern notion of democracy is said to originate with the sociologist Max Weber, who conceive of it as "a political system in which people are defined as participants in the polity (the state) rather than as passive subjects. Central to Weber's notion of participation is the understanding of what it means to be "a citizen" (Kivisto, 2010). For Weber to be "a citizen" means that one is able to participate in the decision-making process and the policy formulation as well as to participate in choosing leaders.

From this conceptual foundation, at least three conceptions of democracy have evolved: Liberal, Deliberative and Participatory Democracy (Meijer, 2011). Liberal Democracy is based on a liberal – and highly individualistic – conception of democracy; with free and fair elections and a competitive political environment, where individual interests form the input for democratic processes. The concept of democracy underlying this perspective is that the more we inform the voters, the better (or more rational) voting behaviour and decision-making process we can expect. The principal proponent of this model is Joseph Schumpeter (Schumpeter, 1962).

Deliberative democracy has the focus not on the election-process, but on the public debate. Democracy is decision-making by means of arguments and deliberation (rather than voting), which are central for political participation. The concept of democracy underlying this perspective is the inclusion of different interests, equality and mutual respects for different political voices in society. Furthermore this perspective addresses the importance of citizens communicating and debating their political opinions in public spaces, through social media, in opposition to public debate carried out between opinion leaders. The principal proponent of this model is Jürgen Habermas (Habermas, 1984).

Participatory Democracy focuses on actual citizen engagement, rather than the debate (Deliberative Democracy) and the election processes (Liberal Democracy). This perspective extends the domain of political participation and political decision-making processes, to include the activities taking place in, for instance, workplaces, local communities or voluntary initiatives driven by citizens. The concept of democracy underlying this perspective is that citizens can be involved not only through words and debates, but also in actions that will produce public values, for instance in creating safe schools for their children or in making their neighbourhood a better place to live. Interestingly, the need for government involvement in participatory democracies is reduced – or not needed at all. The principal proponent of this model is Alexis De Tocqueville and Harry Chatten Boyte (Boyte, 2005).

Democracy hospitalized

Obviously, these three forms of democracy are not mutually exclusive, but can co-exist within a society or governmental system. From this conceptual backdrop, we can derive and stipulate three forms of patient democracy and shared decision making, which could be designed for in healthcare.

1) Liberal patient democracy would entail that patients have direct or indirect influence the managerial decision-making authority at a hospital or on the services that a hospital provides

(treatment, care, facilities, etc.). Examples of liberal patient democracy could be seen in patient's logistical influence over choice of healthcare provider, while they do not have a say in managerial matters, and only little if any clinical influence over proposed treatment patterns (cf. Saltman, 1994, p. 214).

2) Deliberative patient democracy is where patients and doctors share information on equal terms and make decision accordingly. This means that the condition under which shared decision-making is practiced should be based on equality with the inclusion of different interests and arguments of the patient and staff. Today, even though the patient is met by the rules and control of the hospital (institutional clothing, eating at scheduled times, waking at certain times etc.), the patient is increasingly accepted as a competent and valuable dialogue partner during treatment. In most western countries patient involvement, shared decision-making and consent are recognized by law. In Denmark the "Law on Patients' Rights" was given on 1 of July 1998. This law states that "no treatment may be initiated or continued without the patient's informed consent" (Chapter 2, § 6). Such a law is supportive of deliberate patient democracy. Another example would be special interest patient groups arranging cafés or using social media to exchange ideas and sharpen opinions.

3) In participatory patient democracy the patients (or the patients, relatives and staff together) undertake a number of local actions in order to produce public value in terms of better environments and improved medical treatment for themselves. One example, described by Storni (2013), would by type 1 diabetes self-care practices, where patients participate in self-management while also communicating valuable insights to healthcare personal concerning requirements of chronic care.

These three forms of patient democracy hardly ever exist in a pure form within healthcare. Rather they are always challenged and countered by existing organizational and political structures constraining the unfolding of democracy. For designers working to increase patient democracy it is of vital importance to be able to discern such constraining structures and to work out methods for making these structures malleable for citizen participation. In design research there are already a number of approaches available which in one way or the other address the relationship between design, democracy and power. In the next section, we provide an account of participatory design, adversarial design and design activism thereby pointing towards design's potential for re-distributing power and authority in healthcare.

Disruptive design for Democracy: Participatory Design, Adverserial Design and Design Activism

Participatory Design

Participatory design emerged in Scandinavia in the 1980s motivated by a growing desire among designers to involve skilled workers directly in the design and organizational processes at their workplaces. More recently, participatory design has made a shift "from work oriented productive activities to public spheres and everyday life" (Björgvinsson et al., 2010). Thus, the focus is no longer on "democracy at work" but on "democratic innovation". Björgvinsson et al. make a distinction between two kinds of democratic innovation.

According to one interpretation, democratic innovation is primarily concerned with developing and making discrete objects and products. Here stakeholders and lead-users (in the sense of Hippel (2005) are involved in the design process in order to gain access to more information and tools for making smarter products. While this kind of innovation is often claimed to be democratic in the sense that it hands over control and power to users, Björgvinsson et al. criticise it for relying on a

suspect rhetoric being that “the market economy, which increasingly thrives on the speed of producing novelty products, is a precondition for democracy” (Björgvinsson et al., 2010, p. 42).

As an alternative, the authors suggest a second approach to democratic innovation modelled along the lines of social innovation. In so doing, they argue for democratic innovation as a process for radical social change, in developing services, systems and environments, which support more sustainable lifestyles and consumption habits. Rather than a product-centric approach, they argue for increased citizen participation. Central for achieving this aim is the ability of the designer to construct so-called *agonistic public spaces*. Spaces, wherein any narrow market-driven and economical concerns are suspended in favour of a focus on socio-material assemblages, constraining power relations and “the empowering of resources to weak or marginalized groups” (Björgvinsson et al., 2010, p. 43).

Adverserial Design

The idea of agonistic spaces being central for designer’s attempt to create enhanced democratic conditions for people in society is also present in DiSalvo’s notion of “adverserial design” (2012). Adverserial design is modelled on a categorical distinction within political theory between ‘politics’ and ‘political’ (Laclau & Mouffe, 2001; Mouffe, 1998). ‘Politics’ refers to the means and structures that enable a nation, state, region, or city to be governed. Among such structures are laws, procedures of decision-making, systems of election, legislation, and public regulation of people’s behaviour in the urban environment. In contrast, the ‘political’ is a condition of society, of on-going opposition, disagreement and contest, which Laclau and Mouffe deem is a prerequisite for democracy. According to this view, a hegemonic society is a threat to the democratic condition if it rules out spaces of agonism, pluralism and dissensus.

By translating these theoretical ideas into forms of design, DiSalvo comes up with a distinction between Design for Politics and Political Design. “Design for politics” is when design practice works for or supports those in power (e.g the design of a campaign or improving election procedures). In contrast, political design or adversarial design, as he later renames it, is when the object and processes of design are used to create spaces of agonism, which reveal and contest existing political structures and power in a society.

While Björgvinsson et al. uses spaces of agonism to contest market economy and the constraints that Neoliberal ideologies place on participatory design, DiSalvo conceives of agonistic spaces as being primarily targeted against decision makers and governmental authorities. A vivid example of this, is his mentioning of the Million Dollars Blocks project by the Spatial Information Lab who use data visualization of crime statistics as a means for making visible that the US-government is spending more than $1 million dollars annually to re-incarcerate residents from a set of city street blocks in five major US cities. In so doing, this example of adversarial design redirect the attention of politicians away from the sites where crimes are committed to where the criminals live pointing towards needs of designing social programs and addressing housing problems.

DiSalvo’s notion of agonistic spaces is valuable for understanding how design may work against existing structures in order to make hidden agendas visible. Yet, DiSalvo says only little about how the contesting and re-negotiation of power is evoked by the introduction of disruptive design processes, and practices. Also, there is a blind spot in his work as to how adversarial design holds a potential to enable people and citizen to take active part in social change. In order to account for how agonistic spaces must be regarded as the effect of a truly critical aesthetic practice, and how it may arm people with the power to take action, we turn finally to recent work on design activism.

Design Activism

In its political form activism often manifest itself as a protest, demonstration, strike or other form of political resistance; resistance against “an injustice” that a certain societal group cannot accept, do not agree on or wants to make the outside world aware of. In design activism the activist act is not taking the form of a political protest; it’s a form of resistance, enacted in a designerly or artistic way with the purpose of subverting and disrupting power structures so that a redistribution of bodies, ways of doing, acting, roles and identities can take place (Markussen 2013).

By drawing on the philosophy of Jacques Rancière, Markussen has shown that design activism relies on a ‘disruptive aesthetics’. It’s aesthetic effect lies simply in it’s rupturing and unsettling of the self-evidence with which a system of power generally distributes ways of doing, determines who has the right to speak, who must listen, what is deemed appropriate and what is not (Rancière, 2009). By unsettling a system of power, design activism opens up the system for re-negotiating, who has the right to speak, what people are allowed to do and what they may feel about this doing. This interweaving of aesthetics and politics is captured by Ranciére’s notion of ‘aesthetic dissensus’, which is not an effect resulting from acts of striving to overturn or overtake institutional power. Rather, aesthetic dissensus follows from non-violent acts that disrupt the self-evident ways in which existing systems of power control and dominate certain groups in our society. This unsettling of power might create spaces that enable new processes of participation and identity making. In this sense, aesthetic dissensus is related to agonistic spaces, but the difference is that it foregrounds agonism as the rupturing effect of a critical aesthetic practice rather than of a political act.

Participatory Design, Adverserial Design and Design Activism are approaches, which enable design researchers to make detailed inquiries into various conditions for democracy. They all seek to increase democratization, and they all practice “Design for Democracy”, yet in different ways and with different foci of attention. Table 1 sheds more light on their different aims, methods and means:

Design for Democracy	**Design Aim**	**Means**	**Using methods such as:**
Participatory Design	- design new infrastructures - shift from products to designing socio-material collectives (Design Things) - to provide alternative models of cultural production and material fabrication	- co-design activities between designers, users, stake-holders and people from other disciplines	- probing, making tangible things (together with non-designers), enactment by setting users in future scenarios, creating diaries or blogs with users, various forms of co-design workshops within organizations.
Adverserial Design	- reveal and contest hidden power structures - raising critical awareness through design products	- agonistic spaces targeted at political systems and governmental decision makers	- radical cartography, data visualization, adversarial design prototypes.
Design Activism	- reveal, contest and disrupt hidden power structures - empower people to take action in a process of continuous social change	- aesthetic dissensus and agonistic spaces as a means for re-negotiating roles, identities and action potentialities within existing power structures	- détournement, guerrilla tactics, urban interventions and subversive tactics in public space.

Table 1

Proponents of participatory design place great emphasis on designing *infrastructures* understood as innovative milieus, fab labs or other collaborative DIY production facilities where marginalized

members of society (immigrants, homeless, unemployed youth) are offered a space for culture production. The conceptual understanding of participatory design is in this instance developed from Science and Technology Studies and democratic freedom is conceived of as a freedom for all to produce or fabricate.

Adverserial design is focusing on how design can serve as a political instrument to encourage people to reflect critically upon the limitations of ideologies and political power. DiSalvo's notion of agonistic spaces is borrowed from political theory and offers a political conception of designs subversive potential for questioning ruling opinions and values.

Design activism is focusing on how subversive acts can be used in a designerly way to change everyday forms of experience and social interaction. In contrast to adversarial design, design activism does more than reveal and contest hidden power structures. It disrupts these structures at the level of people's experience so that new forms of identity, democracy and citizen power can emerge. Design activism is also different from Participatory Design insofar as it does not aim to found subcultural institutions that can exist as counter publics within a society (such as Malmö's Living Lab). Design activism is instantly played out in public space in order to repurpose ways of living and being together, not new forms of infrastructure.

Design case: Using agonistic spaces and disruptive tactics to prototype patient democracies in healthcare

Our design case consists of three explorative design experiments (Brandt & Binder, 2007; Redstrøm, 2010). The experiments were carried out in the autumn 2013 in collaboration with the Department of Oncology and the Health Service Research Unit, at Vejle Hospital in Denmark. The aim of the experiments was to increase knowledge of the hospital's own conception of democracy as it becomes manifest in the patient democracy initiative at the cancer unit. Additionally, we wanted to examine the conditions for "the democratic" when being hospitalized. In particular, we wanted to uncover the condition under which "shared decision-making" is practised during patient-doctor consultation as well as the condition under which communication and certain services are practiced in other hospital-situations (e.g. the waiting room situation or the visiting hours).

In our research we initially set up the three design experiments with the purpose of using agonistic spaces and aesthetic dissensus as means to prototype various forms of patient democracy. While both participatory design and adverserial design have inspired us, our approach is primarily grounded in design activism.

We differ from participatory design insofar as we do not deem the means of co-design, and the invitation to non-designers to participate in the design process, as appropriate for our initial experiments at the cancer unit. The consultation where doctors inform patients for the first time that they have cancer was the context of some experiments. Here cancer patients find themselves thrown into a life crisis, and the idea of engaging them in the design process seemed unethical and disrespectful. Design activism, on the other hand, allows the designer to step into the role of the patient and to make use of prototyping techniques to get a grasp of the democratic conditions (or the lack thereof).

Our approach also differs from adversarial design. Insofar as our research aims to clarify the notion of democracy that underlies the patient democracy initiative at the cancer unit, the project is to a certain extent targeted at the decision makers and management at the hospital. In this sense it could be confused with adversarial design. However, our focus is not on the subversive effects of design vis-à-vis the political system, but on how design at the level of patient experiences as well as patient-doctor interactions disrupts the political system.

The three experiments offer insights into the implications that each of the three notions of democracy (the liberal, the deliberative or the participatory) would have concerning “patient democracy” and “shared decision-making”. The design research method used replaces existing realities with alternative “disruptive” realities. These disruptive realities can be seen as agonistic public spaces and aesthetic dissensus that open up for prototyping democracy through the acts of interruptions. Before we move on to the experiments we need to explain the particular approach in using disruptive design practices as part of our method.

Experiment 1: Investigating the condition under which “shared decision-making” is practised during patient-doctor consultation.

Method: First a field-study was conducted to investigate the particular patient-doctor consultation and how the communication between doctor, nurse, patient and family member is practised. The design researchers visited in total six patient-doctor consultations and one morning conference between doctors and surgeons. Here the researchers made use of notation and drawing to record the situation, since interfering, recording and photographing the patient-doctor interview/ morning conference, was not permitted. After the field study the interaction between nurse, doctor, patient and family member was enacted (role played) to re-establish and re-play the actual patient-doctor relation (fig.b and fig.c). Finally role-play in combination with photo-annotation was used to construct a series of alternative disruptive realities, in an attempt to activate spaces that could increase democratization (fig. d, e, f, g, h).

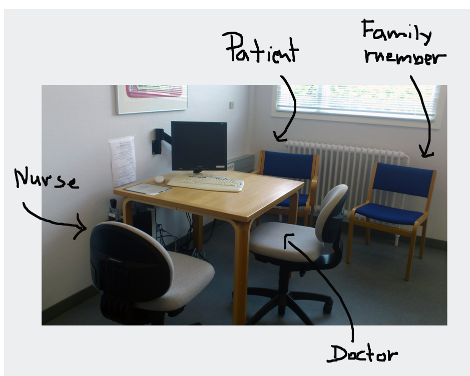

Figure a. The actual consultation room at the hospital

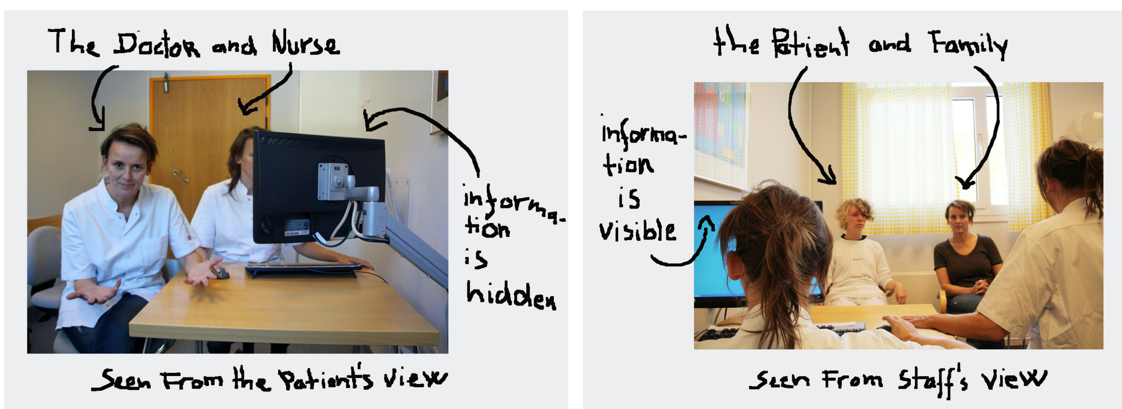

Figure b. (left): The actual doctor-patient consultation (role-played) seen from the patient’s view.
Figure c. (right): The actual doctor-patient consultation (role-played) seen from the staff’s view.

In figure b and c, the re-enacted situation makes it clear that the patient information (on the computer screen) is only visible to the staff, but hidden from the patient and family member. In the following pictures (figure d, e, f and g) role-play in combination with annotation is used to construct a series of alternative disruptive realities.

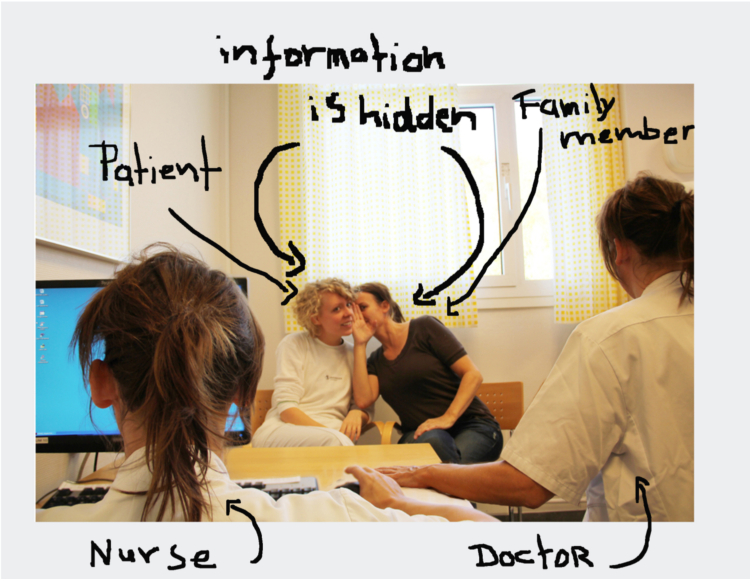

Figure d. Alternative reality: The patient hides information from staff.

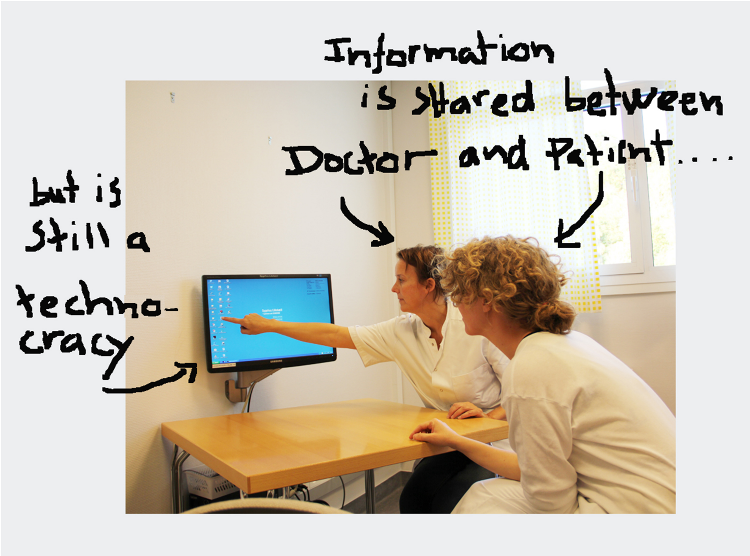

Figure e. Alternative reality: The doctor shares Information with the patient,
but the process of shared decision-making is taking place in a technocratic environment.

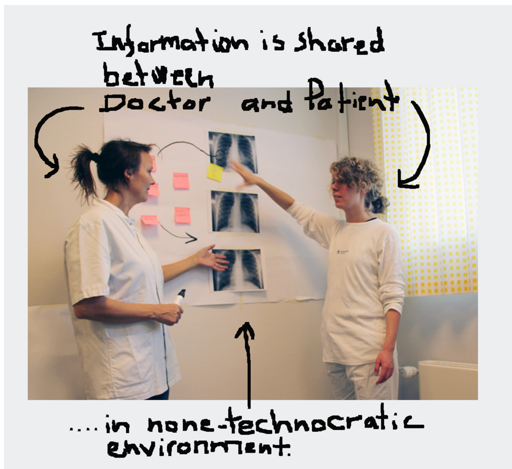

Figure f. Alternative reality: The doctor shares information with the patient, but now the process of shared decision-making is taking place in a none-technocratic environment.

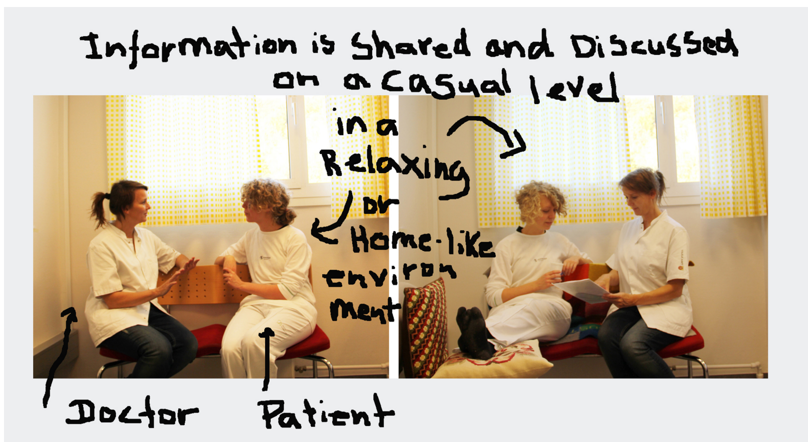

Figure g. Alternative reality: The doctor shares information with the patient and the process of shared decision-making is taking place in a none-technocratic and home-like environment.

Figure h. Alternative reality: The doctor shares information with the patient and the process of shared decision-making is now taking place outside the hospital.

Experiment 1 investigates the limits for the hospital, in terms of how far we can extend the concept of democracy. In figure d the patient and family member whispers to each other in order to unsettle the technocratic structure of the consultation; they share secrets and hides information, in the same way that the doctor and the nurse share and hide information, from patient and family member in figure b and c. Both situations are undemocratic. In figure e the process of shared decision-making is taking place in a technocratic environment (with the computer as focal point, and the staff controlling this) but at least the doctor and patient can see the screen at the same time. In figure f the computer has been removed entirely and the doctor and patient discuss the treatment independently from technology. By replacing the computer screen with a series of x-ray photos and "blackboard" with comments from both the doctor and patient, figure e suggests a professional learning space, where the patient is accepted as a competent and valuable dialogue partner. In figure f the process of shared decision-making is moved from the professional learning space and taken into a more casual, home-like environment, suggesting a friendship between doctor and patient. Yet, the power relationship between patient and doctor is still guided by the fact that we are still in the doctor's domain, in the medical consultation room. In figure g the dialog between patient and doctor is taking place outside the hospital (and removed from the doctor's domain) suggesting a "walk and talk" dialog in nature. The last situation is neither technocratic nor home-like; it suggests that the process of shared decision-making could take place in a complete different environment than the medical consultation room; it suggest a dialog between two human beings, both moving on unfamiliar terrain.

Experiment 2: Investigates the liberal conception of democracy in the waiting-areas of the hospital

Method: First a field-study was conducted, focusing especially at the waiting areas and the chemo-treatment waiting-rooms (figure i.) Secondly the researchers enacted this waiting "situation". Finally role-play in combination with photo-annotation was used to construct an alternative disruptive realitiy (figure j and k)

Figure i. The actual waiting areas at the hospital; all populated with danish gossip magazines.

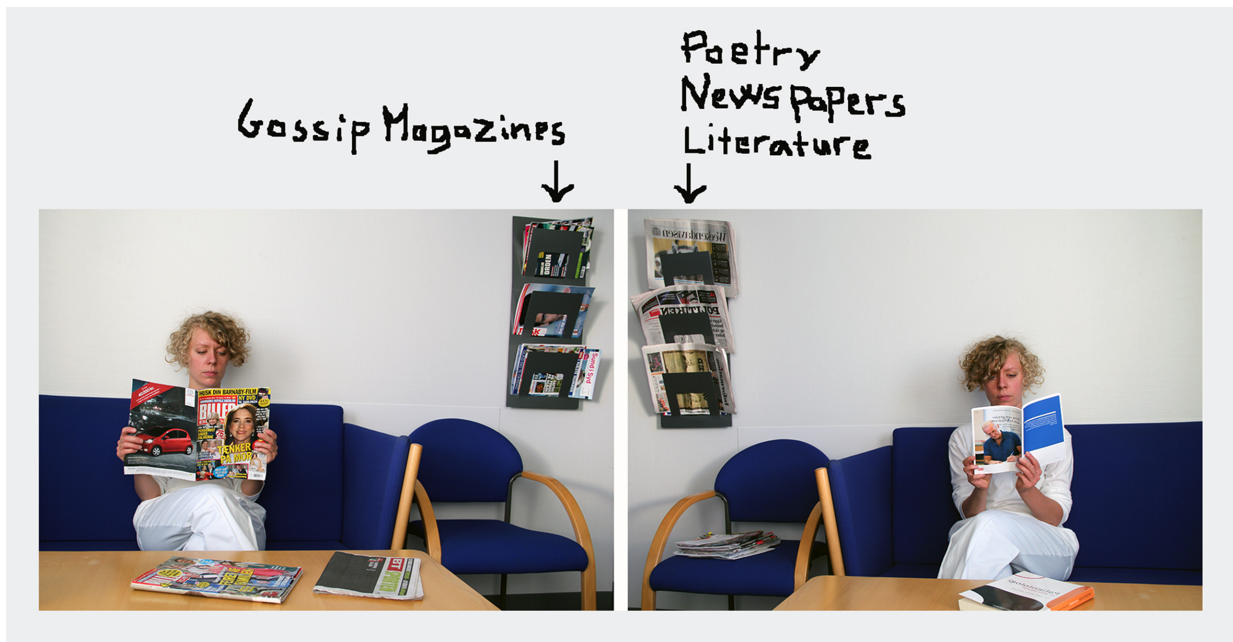

Figure j and k. Alternative reality: The patient has a free choice of literature:
A variety of gossip magazines (right) or a completely other kind of literature, renowned newpapers or poetry (left).

The literature at the hospital basicly consists of gossip-magazines, sensationalist journalism or hospital-folders. Other literature like renowned newspapers or poetry, does not exist. Experiments 2 investigate individualism through the act of waiting. When we wait in the hospital we read, we think or we entertain ourselves in a way that we do not disturb others. Figure k and l, suggest that the literature in the waiting areas ought to address different individuals and different political voices in society; both those who likes to read popular gossip magazines as well as those who like to read poetry, literature, a renowned newspaper or books especially for patients.

Experiment 3: Investigates how the participatory conception of democracy is practised in hospital corridors and in the patient-rooms

The method is almost the same as in experiment 1 and 2: First a field-study was conducted; secondly photo-annotation was used to construct an alternative disruptive reality. The focus of this third experiment was to reveal or stimulate participation that would produce value for the patients and their families.

We looked at the aesthetics of things (objects placed in the patient room) as well as the communication between patients and their families. We ended up focusing at one particular ritual; that of (friends and families) bringing flowers to the hospital. Our study shows that the ritual of bringing flowers usually take the flowing form: the families brings (unique) flowers to their loves ones to make them feel better. They make use of the hospitals vases; a collection of uniform metal vases that all have the same aesthetic qualities (or the lack thereof): vases that resembles sports trophies or funeral vases; all the same size; all easy to clean; all very institutional.

Figure l: The actual vase-corner at the hospital. All vases are the same.
In the cupboard all old vases left by relatives are being stored.

Figure m: Alternative reality: “The Free Vase Collection” project: Gives patient’s and their family the opportunity to choose an unique vase, bring their own (favourite) vase or leave a vase for others.

“The Free Vase Collection” project is explained with a note hanging on the cupboard door (below the vases). The note says:

Dear Patients and Family-members
In this cabinet is a collection of both new and old vases
which people before you brought with them
You can freely take any of these, for your flowers.
You are also free to bring your own vases from home.
If you do not take them with you again,
the vases will get their place here,
in the Free Vase Collection.

Experiment 1 encourages people to break with the institutional way the hospital's handles the ritual of giving/bringing flowers to the patients. The project is engaging people; it says: "you don't have use the depressing, metal, funeral-like vases this hospital offers you. You are free to bring your own vases, leave your vase or re-use those of others". And in doing so, the patients, the family of the patients and the staff help each other building up a unique collection of vases. The hospital management is not needed for this process.

Discussion

Experiment 1 deals with the deliberative conception of democracy in questioning whether the condition under which patient-doctor consultation is practiced, is based on deliberation. Through a series of disruptions - where one disruption leads to the next one - experiment 1 gives us several examples of hidden power structures, thereby offering several entries to how the space for re-negotiation could be activated. At first, it seems as if the balance of power is in the favour of the doctor who has access to all the information (fig. b and c), but throughout the series of disruptions the balance of power shifts in favour for the patient. This is most clearly seen in fig. g where the process of shared decision-making is taken into a casual, home-like environment, suggesting a friendship between the doctor and patient. Seen from psychological point of view, such a form of patient-doctor consultation would be highly undemocratic for a doctor to undertake 8-9 times a day. The power balance seems most democratically distributed in fig. f. where the doctor shares information with the patient in a none-technocratic environment, suggesting a professional learning space, where the patient is accepted as a competent and valuable dialogue partner – not suggesting any form of close relationship.
Experiment 1 clearly shows how fragile the involvement of different interests are and how mutual respect (between the two parties) must be carefully balanced to achieve equality and democracy.

Experiment 2 investigates the liberal conception of democracy and individualism in questioning, what would happen if the hospital would allow a more liberal influence on the services they provide. The disruptive reality presented in experiment 2 does not offer several entries to how the space for re-negotiation could be activated; it merely flips the very well-known construction we have at almost every (Danish) hospital waiting-room situation (the patient having a very limited access to prober literature) into a new construction (the patient having an unlimited access to prober literature).
In that way experiment 2 suggests a more liberal view of the patient – being an independent individual with a variety of cultural and social interests – and not as it is now: a socially excluded view of the patient being a person that consumes gossip-magazines and sensationalist journalism. Experiment 2 does not change the act of waiting, which in itself is undemocratic, but by reshaping the waiting room into an alternative kind of library, containing useful knowledge, different forms of literature and various branches of entertainment, experiment 2 proposes to soften the waiting situation and make it more comfortable and tolerant for a broad group of citizens.

Experiment 3 offers a particular process of how the space for re-negotiation could be activated and suggests a participatory strategy that produces public value; an unique collection of vases that is maintained (and used) by the patients and their family. Experiment 3 is interesting in several ways. First of all, all the basic conditions for practicing the participatory conception of democracy in relation to the ritual of giving/bringing flowers is available; the relatives of patients already brings alternative/ unique vases; the staff do not throw these vases away but actually stores them in the cupboard; the patient/patients could easily have access to unique vases, if they knew that they were allow to use them. Experiment 3 just activates all the ingredients, which are already co-existing in the hospital (for sharing each others vases). Secondly experiment 3 gives us several examples of hidden power structures; the power structure between staff and management (who for a decade has been using uniform, metallic vases); the power structure between staff and patients (who refuses to make use of the uniform vases); and finally the power structure between the

patients and the visiting relatives (who out of empathy brings flowers and vases for their hospitalized relatives and friends). Experiment 3 shows us how easy it would be to re-negotiate and change what people are allowed to do (and has been done for decades in the hospital) – by creating a space of agonism that overturn several power structures at the same time and makes room for actual citizen engagement.

Conclusion

In this paper we have attempted to increase understanding of two key concepts: patient democracy and shared decision-making. We have examined different theories of democracy and the democratic practices that belong to each of these. To understand how patient democracy may be significant in a design research context, we have positioning ourselves within design activism. Design activism is suitable for our purpose, since it is less concerned with the actual political or economical condition and more concerned with the relationship between people's doings and feelings; and it is precisely in understanding this relationship, a space for re-negotiation can be activated

To use design activism to re-negotiate the roles and rights for patients we have set up a series of disruptive design experiments at the Oncological Department at a Danish Hospital. Our experiments contribute with new knowledge in several respects. First of all it gives us knowledge about the hospital's own conception of democracy and how it is manifested in their practice of patient democracy and shared decision making. Secondly the experiments give us knowledge about how to prototype democracy through disruptive design practices and design experimentation.

What we did not have space to discuss is the type of knowledge that is embedded in disruptive design practices and how we should evaluate the value of such knowledge for design research. Such a discussion will be taken up in future work.

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