

# NAVIGATING CARE IN SOCIAL DESIGN: A PROVISIONAL MODEL

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## ABSTRACT

The aim of this paper is to show how the value of social design lies in the approach's ability as a caring practice to foster change for vulnerable groups in society. Yet, to achieve such change, social designers must have a navigational tool that allows them to identify and steer through some of the value conflicts that are typically involved in public service care provision. To substantiate this claim, we rapport from two recent social design projects in the public sector dealing with care within criminal justice and healthcare. Building on these two projects we propose a provisional model for navigating care throughout a social design research process in accordance with an organizational level, a professional practice level and an interpersonal level.

## INTRODUCTION

One central question being scrutinised in current discussions on social design is how to account for the social value achieved through this research practice. In this paper we argue that the value of social design lies in the approach's ability to address and enable care for people belonging to a disadvantaged group. Further, to account for the social values of designing for care means, among other things, understanding how to navigate through diverse value conflicts in a project.

In this paper, the question of how to navigate caring practices in-between value conflicts has been prompted

inductively by social design projects in two public sectors: criminal justice and healthcare. Based on these projects, this paper outlines a provisional model for understanding the provision of care as an analytical attention to the interlacing of multiple levels along the trajectory of an unfolding design project. In providing examples from the two case projects, we wish to engage with questions of how to account for the impact of social design at different stages of the process, while navigating the complex and often unpredictable conditions for designing in the public sector. The aim of introducing a provisional model is to show how the diverse (and often conflicting) values at various levels may provide fertile analytical grounds for identifying changing conditions for social design situated within different phases of the research engagement.

The two case projects both engage problems pertaining to vulnerable groups through similar methodological approaches centred on long-term collaborations with broad stakeholder involvement by means of workshops, co-design, and the subsequent development and testing of a material artefact and service addressing the identified problem.

In case 1, the design consists in a social board game called *Captivated*, which is handed out to children and their incarcerated fathers to be played during in-visits. The game aims at making the prison visit more enjoyable and meaningful - and to make it more tolerable to meet in a difficult situation (the prison visit) and talk about matters that may be affected by taboos, deprivation or shame. Case 2 *The Patient Empowerment Kit* is a self-help package designed for and with cancer patients, which allows patients and their families to talk about existential matters as well as explore opportunities and tactics for increasing life quality before, during and after treatment.

In both cases, care is understood as the capacity to give or receive care across a wide spectrum of configurations. Care concerns - among many others aspects - the attention to and co-construction of care practices on a number of levels (Mol, 2008; Mol et al.,

2015). In the context of the projects presented in this paper, social design is identified and analysed as being caught up in a mesh of divergent organizational structures and regulations, professional practitioner's care for children of prisoners or cancer patients, and caring in relationships between these children and patients and their families.

To set the scene, we start out by providing a clarifying account of the concept of care and how it lends itself to various interpretations. By taking our point of departure in Fine's *A Caring Society?* (Fine, 2007) we identify three different forms of care, which are useful for conducting a nuanced analysis of how care is practiced in welfare services. Hereafter, we draw upon some existing research literature in order to show how social design at its core must be understood as a caring practice. Summing up on this largely theoretical part, we then introduce three different levels, which are constitutive of our provisional model: the organizational level (macro), the professional practice level (meso) and the intimate interpersonal level (micro).

Subsequently, we examine the two social design cases as involving four central phases in the project development, namely a) *establishing strategic relations*, b) *organising collaborative co-design workshops* c) *interaction with materialized design prototypes* and d) *evaluation of design intervention*.

On the basis of this examination, we finally integrate the three levels with the temporal phases in order to introduce a provisional model that allows us to point out some of the value conflicts that are conditioning social design as a caring practice.

## CARING IN SOCIETY

Caring in society has moved from the private or domestic sphere (in the form of informal care) to the public domain and institutions (formal care). From being an unpaid job primarily undertaken by women to maintain the home and the well-being of the family, caring today has become integrated as part of an institutionalized network of care services provided by the state or human service facilities to address the increasing demands of child care, elderly care and to nurse those who are ill or unable to take care of themselves.

But the concept of care cannot just be reduced to the distinction between unpaid family work and paid care professionals or to the binary pair of informal versus formal care. In Scandinavia, for instance, family members can be paid to take care of their family members in their own homes, in case of a life-threatening disease. Moreover, in Denmark children who are challenged or have fragile parent-child relations can be appointed a "professional" adult friend to help and guide them. In these two cases there is no clear division between "family" and "paid sources", informal

and formal (see also Sundström et al., 2006)

To establish a more fine-grained understanding, it may be helpful to use Wearness' distinction between "care-giving work" and "care", which allows her to identify three basic forms of care (Fine, 2007, p. 84; Waerness, 1989, 1984):

- 1) Caring for dependents: Caring work in which the recipient is incapable of self-care and therefore dependent of caregiver. Here, the care recipient has little or no power (is helpless) in relation to the person giving care.
- 2) Caring for superiors: Caring work that might take the form of a personal or domestic service, for instance a housekeeper or personal assistant being paid to provide care. Here the care-recipient is superior to or the employer of the caregiver.
- 3) Caring in a symmetrical relationship: Caring work that can be characterized as "caring for each other" – a more balanced relationship of "give and take", for instance between partners, friends or family members.

"Care-giving work," in this taxonomy, has to do with the care-activity to provide help and support, whereas "care" in addition involves a mind-set, attitude, affection and concern for the other. In Wearness' framework "care-giving work" does not necessarily involve "care". This depends on the relation between care recipient and caregiver.

Furthermore, Fine (2007) argues that it is not possible to conceive of care, without recognition of the body. The need for care thus arises primarily from the physical incapacities of the care recipient. From the caregivers side, the response to provide care, involves culturally shaped as well as socially constructed actions (Fine, 2007, p. 194). Following this line of thought, an analysis of caring practices must therefore also include an examination of how for instance socio-cultural beliefs, institutionalized routines as well as organisational structures influence the caring for the recipient's body. Something that becomes important when we below turn to the contextual setting of our two cases: the prison and the hospital.

To fathom this complexity, Fine defines care as "a contested, multi-layered concept that refers not just to actions and activities, but to relationships and to values and attitudes about our responsibility for others and for our own being in the world" (Fine, 2007, p. 4).

In his thorough analysis of how capitalism has radically transformed welfare services, Fine furthermore demonstrates how hybrid forms of informal and formal care have occurred, which rely upon partnerships between civic society and public/private institutions (see Fig. 1).

	Informal Care (primarily care of particular individuals)	Hybrid forms of Care (care of particular individuals/ strangers)	Formal Care (primarily care of strangers)
Unpaid	Fx Familiar care (at home) Informal care networks	Fx Care shared by family and formal services (paid and unpaid)	Fx Human Service Volunteers
Paid	Fx Domestic employees such as nannies	Fx Care allowances Use of private domestic help	Fx Paid care workers Professionals

Fig. 1: Model reprinted from Fine (2007)

This model can serve as an initial backdrop for understanding basic forms of caring practice.

### SOCIAL DESIGN AS A CARING PRACTICE

Social design is generally conceived as a caring practice that responds to the vulnerability and needs of marginalized societal groups. In its concern for social problems, social design can easily be conflated with social innovation. But as Manzini (2015, p. 64) rightly points out we need to be aware that the adjective ‘social’ takes on two different meanings depending on whether we talk about social innovation or social design.

In social innovation, the social denotes a concern for repairing systemic or structural errors for the common good. Typically, such errors require of a society that it reinvents its economic models or service infrastructure. For instance, in the Samaritanian Mobile Care Complex in Latvia a complex infrastructure is designed combining a number of services (daily grocery delivery, neighbour watch, alarm clocks, and so on) to enable elderly people in rural districts to stay as long as possible in their own homes. In so doing, the project aims not only to address the current lack of elderly care, but also to reinforce the social fabric by establishing caring relationships between elderly people and local residents. It is hoped that rural districts will thereby become more resilient toward the intense and on-going process of urbanization.

In social design, according to Manzini (2015, p. 64), the social “indicates the existence of particularly problematic situations (such as extreme poverty, illness, or social exclusion, and circumstances after catastrophic events to which both the market and state fail to find solutions, and which therefore pose [...] the need for urgent intervention from some other quarter”.

The distinction made by Manzini can be a good starting point for understanding social design as a caring practice. However, we argue that it is necessary to provide some additional criteria to avoid misinterpretations. His exemplifying of social design being concerned with ‘extreme poverty, illness’ or ‘circumstances after catastrophic events’ could easily lead one to believe that social design is confined

geographically to those hot spots in the world where famine and diseases occur as a result of natural disasters and which require interventions from charity or NGOs. But social design can also deal with particularly problematic situations within the welfare state and be exploited by public sector institutions. Hence, it seems more concise to say that what is experienced as particularly problematic is context dependent.

Moreover, social design usually results in social change for a limited vulnerable group of people, not necessarily for the common good or general public. This change is often to be located as a significant qualitative change on a micro level in people’s well-being or interpersonal relationships rather than on systemic structural levels (cf. Le Dantec, 2016; Markussen, 2017; Thorpe and Gamman, 2011).

In working out social design solutions, the people and institutions that are being designed for is usually involved in co-design activities throughout the process from researching, generating and implementing new ways of making social change happen (Armstrong et al., 2014, p. 15). Yet, it is important to notice, as Gamman & Thorpe (2011) demonstrate, that co-design can be practiced as a caring practice quite differently when the purpose is to do good.

A *paternalistic* approach is when designers assume responsibility for solving people’s problems, which the designers themselves identify as the basic need. Here there is a risk of patronizing and making people over-dependent on the designers. Instead of a need-based model, Gamman and Thorpe suggest that designers work with an asset-based approach, where people are looked upon as having valuable resources, skills and competences.

The asset-based approach may manifest itself in two closely related approaches. With the *maternalistic* approach the role of the designer becomes similar to that of a primary caregiver who gives small doses of ‘optimal frustration’ in order for a child to learn and develop on their own. Applied to co-design that means enabling actors “to develop and build their own capacity and resilience, and to draw upon their own assets, rather than focus only on unmet needs” (Thorpe and Gamman, 2011, p. 221).

The *fraternalistic* approach goes one step further insofar as it seeks to “democratise responsibility (and agency) among actors in the co-design process” (Thorpe and Gamman, 2011, p. 222). In comparison to the maternalistic approach caring here is conceived of in pluralistic terms as a collaborative process involving many actors, values and institutional structures.

As social design as a caring practice inevitably rely on the intention of doing good, it usually finds itself caught up in a mesh of value conflicts. For the sake of clarity such conflicts can be identified on at least three different levels. At a macro level, value conflicts may occur between divergent economic models,

organizational structures or managerial logics. At a meso level, value conflicts may be the result of care professionals' practices not being in tune with that of the care recipients' expectations and need for support; or conflicts may arise because managerial decisions are difficult to implement into care professionals' practices and working conditions. At a micro level, people's self-care or family support may not be appreciated by human service facilities and institutions, or public welfare services may only include care for some vulnerable groups, while excluding others. Let us try to exemplify the usefulness of these levels by mapping out the contextual setting of our two case projects.

## MAPPING OUT VALUE CONFLICTS AT THE MACRO LEVEL

Over the last decade, the Danish Prison and Probation Service, which is the host organization of our first social design project, has implemented several initiatives in order to improve in-visits facilities for inmates' children and family. These initiatives are not only made for the sake of children's and relative's well-being, but also as part of an extended process of rehabilitation. By engaging inmates in enduring interactions with their families, it is assumed that they will change for the better and become caring fathers and law-abiding citizens upon post-release. While the value of soft family friendly initiatives are recognised at a macro level by prison management, it collides at the same time with the strict approach of disciplining and controlling the prisoner. In fact, this central value conflict is made explicit in the Prison and Probation Service's statement of its core service consisting in the "art of balancing a strict and soft approach" (see Fig. 2):

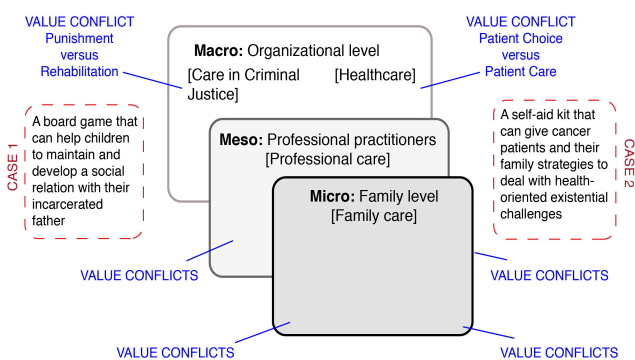


Fig. 2: Value conflicts in Criminal Justice and Healthcare

Danish hospitals, which are the context of our second social design project, find themselves placed in the midst of a paradigm shift. At a macro level decision-makers and healthcare managers previously believed in patient choice being a model, where patients should be able to freely choose treatment at whatever hospital they

preferred to get the best treatment and avoid waiting lists. Much like a consumer choosing between available products on the market. But this model has been found to be socially excluding, it doesn't work in instances of life-threatening diseases and – contrary to many politicians' wet dreams – it has not led to better performing hospitals (see e.g. Fotaki, 2009).

In its place, a new model focusing on patient care is now being tried out, where the patient is looked upon as a partner instead of a consumer (Riiskjær, 2014) and where existential matters of concern and life quality should be valued equally with a medical concern. The values underlying this model are in direct conflict with those underlying patient choice (Mol, 2008).

Such value conflicts, which are represented in blue print in Fig. 2, are very important for social designers to keep in mind, because the success of a project often depend on how agile one is able to navigate through them.

For now, we have only pointed out the conflicts we have faced as social designers at a macro-level. But the conflicts on the meso and micro levels will be made visible in the following sections, as we provide a more detailed description of the two case projects according to different critical phases in the design research process.

## TWO CASE PROJECTS

In this section we will provide a detailed description of our two case-projects; *Capitivated* (a board-game designed for children of incarcerated fathers) and *the Patient Empowerment Kit* (a self-help package for cancer patients).

Figure 3 depicts a simplistic analytical model explaining the two projects according to four phases in the design research process: a) establishing strategic relations; b) organising collaborative co-design workshops; c) interaction with materialized design prototypes and d) evaluation of design intervention.

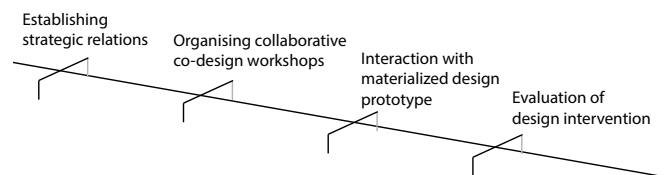


Fig. 3: Model of phases in a design research process

## THE PRISON CASE: THE BOARD GAME *CAPTIVATED*

The game *Captivated* is a board game that has been designed for the Prison and Probation Service's visiting program to help children to maintain and develop a social relation with their incarcerated fathers (Fig. 4). The *Prison Game* is part of the design research project *Social games against Crime* (2015-18) that involves researchers from Denmark, The Netherlands and the UK. Since autumn 2018 *Captivated* has been distributed to all Danish prisons.



Fig. 4: The board game *Captivated*, 2018



Fig. 5: Three types of game cards, *Captivated*, 2018

The game lends its game mechanics from the board game *Monopoly* and takes its players on a journey through a prison with certain places, characters (groups of prisoners and staff) and situations that the players already know – or will learn to relate to.

All characters in the game have families and identities. The player wins the game by collecting certain characters and by performing acts, triggered by the question cards. The game has three different types of

cards; story cards (stories about the prison), actions cards (encourage physical interactions) and "be honest" cards (invite for deeper interpersonal communication between the players).

The intention of designing the game is to improve the quality of visits and to use game elements to strengthen family narratives that are challenged or broken due to parental incarceration. In particular, the game enables the players to share personal stories through bodily interactions and dialogue concerning the fathers' and the children's daily lives.

## DESIGN RESEARCH PROCESS IN THE PRISON CASE:

### ESTABLISHING STRATEGIC RELATIONS

To establish strategic relations and sustainable conditions for the feasibility of the project a series of meetings and workshops were organized. Among these were meetings with the Prison and Probation Service's manager of the child responsible program, local prison management, prison officers; incarcerated fathers, family therapists; children of prisoners and their mothers. In addition, meetings were organized with specialists and researchers within criminology, psychology and game design research. These meetings took place before, during and after the design process and are important for creating a sustainable foundation for both development and evaluation processes.

### ORGANIZING COLLABORATIVE CO-DESIGN WORKSHOPS

During the process of designing the game, several participatory design activities and co-design-workshops were organized, including: 3 design workshops with children, who had a father in prison; 1 workshop with mothers (of children who have a father in prison); 2 workshops with 6 incarcerated fathers; 1 workshop with 30 prison officers; 1 workshop with 2 family-therapists. In this process *design games* formats (Brandt, 2006; Brandt and Messeter, 2004; Eriksen et al., 2014) were used as a method of inquiry. The knowledge gained from these workshops has informed and inspired the game development in relation to how to construct a fictional game world and playful interactions, that align with the actual needs and dilemmas of the children and their incarcerated parents (see also Knutz, Lenskjold & Markussen 2016).

### INTERACTION WITH MATERIALIZED DESIGN PROTOTYPE

The actual interaction with the materialized prototype takes place in three Danish prisons. In this process, 2 incarcerated fathers and their children have pilot-tested the game, during a prison visit. On this occasion three researchers participated and could observe the father and children interacting with the materialized design prototype. After the pilot-test, five families have enrolled into the actual evaluation study. This means

that they have played the game during visiting hours in the prison.

#### EVALUATION OF DESIGN INTERVENTION

Evaluation of the design intervention takes place after families have played the game during one or two visits. The father is interviewed in the prison. The children are interviewed at home, in the presence of their mother or foster parent. The purpose of these interviews is to evaluate whether the game enables the players to share personal stories through bodily interactions and dialogue concerning the fathers' and the children's daily lives.

#### THE PATIENT CASE: THE PATIENT EMPOWERMENT KIT

The *Patient Empowerment Kit* is a preliminary design concept, developed on the basis of a number of explorative and participatory processes involving patients, researchers and healthcare professionals (fig. 6). The project is part of a larger EU funded research project, which aims at developing concepts that can strengthen cancer patient's sense of well-being and life quality through their course of treatment. The kit is still under development but is expected to be pilot tested in 2019-20 in Denmark and Germany.



Fig. 6: The Patient Empowerment Kit, 2018

The *Patient Empowerment Kit* contains tools, tactics, exercises and advices from other patients who have been through cancer treatment and who have received conventional, alternative or complementary cancer programs or therapies.

The intention of the design is to help patients and their families to talk about existential – and often problematic – topics as well as explore coping strategies and tactics for increasing life quality.

#### DESIGN RESEARCH PROCESS IN THE PATIENT CASE:

##### ESTABLISHING STRATEGIC RELATIONS

Since the *Patient Empowerment Kit* should embrace all patients – both those who choose conventional treatment (usually chemotherapy or radiation), as well as the patients who choose alternative treatment it is necessary to establish strategic relations with patient organizations representing different patient groups. For this purpose, meetings were organized with *Kræftens Bekæmpelse*, the Danish Cancer Society, which aligns itself with the public health care program, as well as *Tidslerne*, a grassroots patient association, which represents patients that follows complementary or alternative treatment avenues. The two organizations represent very different opinions and beliefs about what should be deemed constitutive as a reasonable treatment within the public Danish health services and their dialogue has been marked by deep disagreement.

##### ORGANIZING COLLABORATIVE CO-DESIGN WORKSHOPS

In the process of designing the *Patient Empowerment Kit* probing was used extensively as a method of inquiry (Boehner et al., 2014, 2007; Gaver et al., 1999; Mattelmäki, 2008, 2006; Mattelmäki et al., 2016) to obtain a more sensitive understanding of cancer patients' everyday lives, challenges, feelings and decisions in relation to their choice of treatment. For this purpose, a number of probe tasks have been developed which have enabled patients to express themselves through a series of participatory probe sessions. The probe studies have provided the research team with in-depth knowledge of how patients live with cancer in their daily lives, what they feel strengthened by and how coping- and self-care strategies are organized and brought into action (Knutz et al., 2018, 2017). The knowledge that has been gathered has informed the development of the final prototype.

##### INTERACTION WITH MATERIALIZED DESIGN PROTOTYPE

The interaction with the materialized prototype is happening through collaborative workshops involving doctors, nurses, alternative therapists/specialists as well as patients. The purpose of this intervention is to qualify the prototype for further development. These interventions will focus on qualifying the different modules (tools, tactics, exercises) in the kit, identifying where in the healthcare system the *Patient Empowerment Kit* can ideally be implemented and how patients can benefit most from it.

##### EVALUATION OF DESIGN INTERVENTION

After qualifying the different modules an evaluation protocol will be designed. The purpose of this protocol is to evaluate whether the kit enables the patients and their families to talk about existential subjects as well as explore opportunities and strategies for an increasing lifestyle quality.

## ANALYSIS: IDENTIFYING VALUE CONFLICTS

Previously (in Fig. 2) we have identified value conflicts at the organizational level within the prison system as well as in the healthcare system. In the following we will examine more closely how value conflicts are also present at the professional practitioners' level as well as the family level and how we have responded to these divergent values in our design practice. By understanding social design as a caring practice, we will then discuss how to navigate these value conflicts.

### VALUE CONFLICTS IN THE PRISON CASE

In the prison case several value conflicts were identified; especially during the workshops with children, where design games were applied as a participatory method to gain insight into the challenges of having a father in prison.

For one of these workshops a design game was constructed in which the children were encouraged to formulate a so-called "dream card" (a future wish concerning their relation and visits with their father in prison) as well as three barrier cards (obstacles for the "dream" to be fulfilled). One of the children, "Mira", a 14-year-old girl, had a problematic relationship with her incarcerated father who, she felt, was dominating and demanding. Her "dream card" materialized a specific wish to visit the father less frequently. Her three barrier cards revealed that the obstacles for not seeing the father were that it was too difficult for her to tell him; that her father did not understand her personal life; and that he would be disappointed with her. So her desire to visit her father less frequently was hard for her to act out in reality, as her challenges of telling the father how she felt were too difficult for her (Fig. 7):



Fig. 7: One transcribed & translated design game result from the participant "Mira"

The design game materialized – on a micro level - a value conflict that gave the design team a new perspective on the hypothesis of the project. Whereas originally we assumed that the final game should encourage children to visit their fathers more often, Mira's "dream-card" countered this assumption. Our hypothesis was in fact founded upon a recent report made by The Danish National Centre for Social Research that pointed out a need for offering better-designed initiatives to children in the age of 11-18 years. Due to the current lack of such initiatives, it is estimated in the report that these children have higher risk of ending up in psychiatric treatment, placement with a foster family or that it will significantly reduce their educational performance (Oldrup et al., 2016, pp. 5–14). However, through our design workshop with Mira and other children we learned that children do not necessarily want to visit their fathers more often. What instead is important is to improve the quality of the visits by making them more meaningful.

This key finding offers two takeaways: Firstly, it offers an organizational learning at a macro level to the Danish Prison and Probation Service, namely that it should not prioritize higher frequency as important as quality of visits in the shaping of its visiting program.

Secondly, the impact for social design in this instance consisted in a requirement - on our professional practice level - to revise the project's original evaluation study design. Hence, while our initial intention was to evaluate whether the game motivated children to visit more frequently, we decided to let go of this indicator.

In the further process of evaluating our design intervention, we also identified value conflicts. During this phase of the project, the design team worked closely together with the prison officers and criminologists in trying to use a psychometric evaluation instrument (the Inventory of Parental and Peer Attachment (IPPA)) as an evaluation tool. This tool is considered valid in criminology and psychology for its ability to evaluate whether children and adolescents feel attachment security in relation to their parents (Armsden and Greenberg, 1987). By using it in our evaluation it was hypothesized that it would be possible to see whether the game would help children to increase their feeling of attachment, for instance, by enabling them to better express emotions, communicate freely and to be honest with their fathers. The IPPA was pilot tested by a small group of inmates and their children with the help from a group of prison officers who handed out the IPPA-forms to the prisoners.

In this process we learned that psychometric evaluation instruments did not work, as we had anticipated. One of the first indications we received was from an incarcerated father, a 50-year-old man called "Patrick" who in an agitated state had scratched out the entire questionnaire. When, in a follow-up interview, we talked to Patrick, he pointed out that some of the questions simply were too sensitive and painful and

therefore not possible to answer in a questionnaire, whereas a personal conversation would have made him more likely to answer such questions. Subsequently, we received emails from prison officers informing us that even though the inmates in the pilot test responded that they didn't find any problems with the IPPA, in the dialogue with the prison officer they gave a different account. Based on this information and Patrick's response we made a revised version of the IPPA editing out questions, which we regarded as being too intimidating.

However, out of 500 issued forms, we only got 3 back in a completed state. The lesson to be learned from this incident is that social design, as a caring practice must be considered as permeating each and every aspects of the research process. In the evaluation of social design work caring should be manifested in how participants are approached in the evaluation. Consequently, based on the value conflict we experienced here, we decided to radically change the evaluation design into an ethnographically oriented study, focusing on how the game help children and their incarcerated fathers to re-story broken or troubled family narratives. This meant replacing attachment theory with theories of family narratives as the conceptual foundation of the project. Such a study seems more aligned with prisoners' predicament in maintaining informal care, their parenting role and integrity as incarcerated father.

The provisional model below (Fig. 8) illustrates how the value conflicts from the prison are present in the project and how these divergent values impacts the design process:

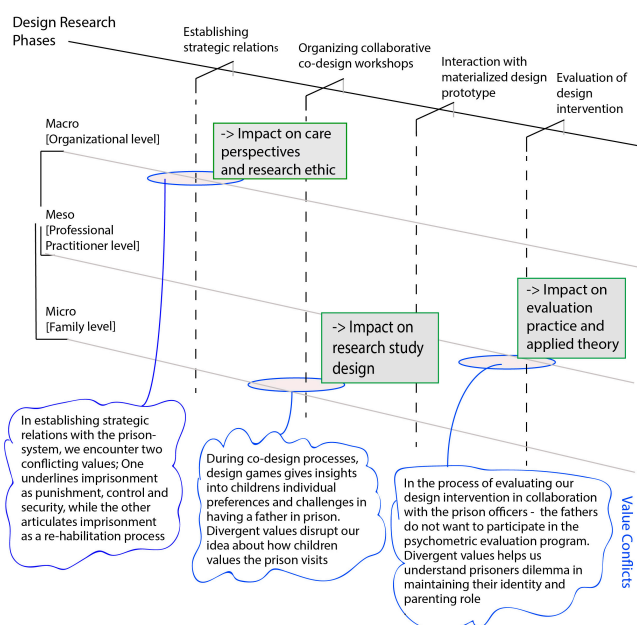


Fig. 8: Provisional model applied to the Prison Case

## VALUE CONFLICTS IN THE PATIENT CASE

In the patient case we identified several value conflicts already from the beginning of the project. We found out that within patient groups shared or conflicting values relied on how cancer patients may comply with or reject the public healthcare system and how their individual participation in treatment might be configured. For instance, some of the patients who align themselves with the patient association *Tidslerne* have found a shared value that is connected to the fact that they have either rejected chemotherapy in favour of alternative treatment avenues or they were in a situation where the hospital had ceased to offer further chemotherapy, because the treatment has failed to produce the intended effects.

We discovered that *Tidslerne* offered cancer patients, who did not have a place in the public cancer treatment program, new values and beliefs in relation to alternative coping strategies and self-care. To incorporate this knowledge into our design, we organised new co-design activities both with patients who were "in the system" (part of the hospital's treatment program) as well as patients outside the healthcare system (who have followed their own alternative treatments). And we decided from an early point to alter our patient profiles and to attempt to incorporate alternative patient identities and values connected to these identities into our design.

As part of the co-design activities probing was applied as a participatory design method to give insights into patients' individual preferences, feelings, motivations and strategies for coping with cancer (see method described in Knutz et al., 2017)

One particular probe study concerns the patient "Ida", a 52 year-old woman, diagnosed with cancer of the pancreas. Using probes (see Fig. 9) in combination with follow-up interviews with Ida we learned that she has participated in a chemotherapy program for several months until the hospital announced that "the chemo did not have the intended effect". Ida is diagnosed with incurable cancer. The doctors set her life expectancy to a few months, but they still want to keep her in the chemo program. Ida objects, because she does not feel that her body can withstand more chemo. Yet, she doesn't want to be dismissed from the public cancer program, which allows access to additional health checks at the hospital and she must fight for permission to be allowed a so-called "chemo-break". At the same time, Ida initiates an alternative natrium-bicarbonat treatment in combination with a strict dietetic doctrine allowing only intake of alkaline foods. Through her alternative treatment, her life quality gradually improves. But it frustrates Ida that she has no dialogue with the hospital about these initiatives. She feels the doctors have no interest in her trying to stabilize the cancer.





Fig. 9: One transcribed & translated probe-return from the participant “Ida”

Through Ida's interaction with the probe, we learned how she constructs a new patient identity grounded in her embodied experience with alternative treatment. Furthermore, we get detailed insights into how she practices self-care and how she shapes a sustainable coping strategy. The value conflicts between what in public healthcare is considered to be “good care” and what Ida and other patients believe is the best for them, informs our final design prototype (the *Patient Empowerment Kit*) both in its division between patient profiles and treatment options (conventional, alternative or complementary cancer programs) as well as how to organize the tools, tactics, exercises in each division.

The provisional model below (Fig. 10) illustrates how the value conflicts from case 2 are present in the project and how these divergent values have impacted the design process:

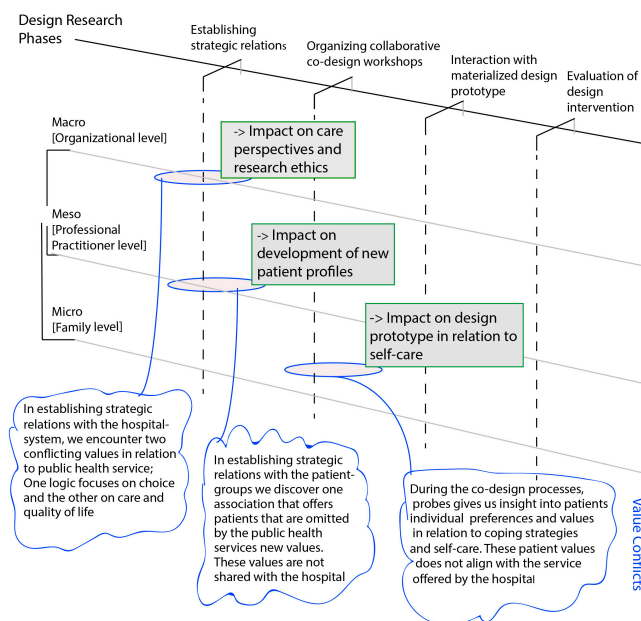


Fig. 10: Provisional model applied to the Patient Case

## CONCLUDING REMARKS

In this paper, we have laid out a model that allows for navigating in-between value conflicts identified and occurring in a social design project. By navigating one should not understand the overcoming of these conflicts. Rather, we conceive of social design as being about mapping and negotiating irresolvable paradoxes and inconsistencies. Engaging with public sector services means buying into the instrumentalization of caring practices to meet societal concerns as well as economic constraints, while at the same time trying to maintain a certain degree of autonomy.

In our prison project we were engaged to design a game that has become part of an existing visiting program that is shaped according to certain agendas, logics and beliefs. In the healthcare project the agenda of patient care was coupled strictly to a neoliberal concern for reducing patient complaints as well as outsourcing care to patients and their family. The challenge here is to avoid letting one’s research ethics, methodological approach and evaluation practice be infected too much by these macro-level influencers.

The spatial limitation of this paper allowed us only to map out some of the many conflicts that were located in both projects on all of the three levels along the process. Yet, we hope that our provisional model can be of use for social designers who work with public sector institutions in order to bring about social change.

## ACKNOWLEDGMENTS

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## REFERENCES:

- Armsden, G.C., Greenberg, M.T., 1987. The inventory of parent and peer attachment: Individual differences and their relationship to psychological well-being in adolescence. *J. Youth Adolesc.* 16, 427–454.
- Armstrong, L., Bailey, J., Julier, G., Kimbell, L., 2014. *Social Design Futures: HEI Research and the AHRC.*
- Boehner, K., Gaver, W., Boucher, A., 2014. Probes, in: Lury, C., Wakeford, N. (Eds.), *Inventive Methods: The Happening of the Social.* Routledge, London & New York.
- Boehner, K., Vertesi, J., Sengers, P., Dourish, P., 2007. How HCI interprets the probes, in: *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems.* ACM, pp. 1077–1086.
- Brandt, E., 2006. Designing exploratory design games: a framework for participation in participatory

- design?, in: Proceedings of the Ninth Conference on Participatory Design: Expanding Boundaries in Design-Volume 1. ACM, pp. 57–66.
- Brandt, E., Messeter, J., 2004. Facilitating collaboration through design games, in: Proceedings of the Eighth Conference on Participatory Design: Artful Integration: Interweaving Media, Materials and Practices-Volume 1. ACM, pp. 121–131.
- Eriksen, M.A., Brandt, E., Mattelmäki, T., Vaajakallio, K., 2014. Taking design games seriously: re-connecting situated power relations of people and materials, in: Proceedings of the 13th Participatory Design Conference: Research Papers-Volume 1. ACM, pp. 101–110.
- Fine, M.D., 2007. A caring society?: care and the dilemmas of human service in the twenty-first century. Macmillan International Higher Education.
- Fotaki, M., 2009. Are all consumers the same? Choice in health, social care and education in England and elsewhere. *Public Money Manag.* 29, 87–94.
- Gaver, B., Dunne, T., Pacenti, E., 1999. Cultural probes. *Interactions* 6, 21–29.
- Knutz, E., Lenskjold, T.U., Markussen, T., 2016. Fiction as a resource in participatory prototyping, in: Proceedings of the 50th Design Research Society Conference. University of Brighton, Brighton, UK.
- Knutz, E., Markussen, T., Birkelund, R., 2017. Inquiring into politics of patient democracy through probing, in: Design + Power. Presented at the Proceedings of the Nordes 2017 Conference on Design + Power, Oslo.
- Knutz, E., Markussen, T., Thomsen, S.M., 2018. Materiality in probes: three perspectives for co-exploring patient democracy. *CoDesign* 1–21.
- Le Dantec, C.A., 2016. Designing publics. MIT Press.
- Manzini, E., 2015. Design, when everybody designs: An introduction to design for social innovation. MIT Press.
- Markussen, T., 2017. Disentangling ‘the social’ in social design’s engagement with the public realm. *CoDesign* 13, 160–174.
- Mattelmäki, T., 2008. Probing for co-exploring. *Co-Des.* 4, 65–78.
- Mattelmäki, T., 2006. Design probes. Aalto University.
- Mattelmäki, T., Lucero, A., Lee, J.-J., 2016. Probing—Two Perspectives to Participation, in: Collaboration in Creative Design. Springer, pp. 33–51.
- Mol, A., 2008. The logic of care: Health and the problem of patient choice. Routledge.
- Mol, A., Moser, I., Pols, J., 2015. Care in practice: On tinkering in clinics, homes and farms. transcript Verlag.
- Oldrup, H., Frederiksen, S., Henze-Pedersen, S., Olsen, R.F., 2016. Indsat far udsat barn. SFI - Det nationale forskningscenter for velfærd, København.
- Riiskjær, E., 2014. Patienten som partner: en nødvendig idé med ringe plads., Studies in History and Social Sciences. Syddansk Universitetsforlag.
- Sundström, G., Malmberg, B., Johansson, L., 2006. Balancing family and state care: neither, either or both? The case of Sweden. *Ageing Soc.* 26, 767–782.
- Thorpe, A., Gamman, L., 2011. Design with society: why socially responsive design is good enough. *CoDesign* 7, 217–230.
- Waerness, K., 1989. Caring, in: Boh, K., Bak, M., Clason, C., Pankratova, M., Qvortrup, J., Waerness, K. (Eds.), Changing Patterns of European Family Life: A Comparative Analysis of 14 European Countries. Routledge, London & New York, pp. 217–47.
- Waerness, K., 1984. Caring as women’s work in the welfare state. *Patriarchy Welf. Soc. Oslo Univ.* 67–87.