

Suffering Beyond Negotiation: Towards a Biographic Perspective on Cooperative Design for Therapy

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Abstract. In this paper we argue that design in therapeutic domains (in a broad sense) depends on an understanding of the background for the engagement of the various users involved. It is specifically argued that an understanding of the life transforming process, or trajectory as opposed to design process and rational process of therapy has to be understood and that a possible cornerstone in such an understanding is a biographic concept inspired by Strauss' concepts of suffering. "Suffering" is discussed as a frame for enabling a subjective perspective to have a voice in design. That is to put a perspective center stage that is not based in the negotiation between rationalities. The paper draws examples from design based research projects over the last 5 years.

1 Introduction

The design of ICT based solutions and artifacts together with users, i.e. participatory design, is a cooperative process. Various actors are involved to collaboratively envision and build technologies for future practice. In workplace settings, the participatory design movement has emphasized the importance of involving workers to capture the various, often contradictory, interests, and to ensure that professional knowledge (including tacit knowledge) influences the design.

In recent years, ICT for the health care sector has been a growing arena for CSCW and participatory design. The health care sector presents a challenge with respect to how we understand collaboration and participation in relation to design. In many cases, the new ICT solution will influence and include patients at an active level. Not only in terms of quality of service, but also as more active participants in medical intervention. This is the case with telemedicine and similar approaches that aim to address the scarcity of medical personnel. Furthermore, this more active involvement of patients is a challenge to the traditional western medical paradigm that has mainly assumed that healthcare professionals and not patients should take an active role.

If patients are not to be understood as passive objects of medical intervention, it is a consequence of the basic ideas in participatory design to involve them as collaborators in the design process. This involvement is a challenge with respect to method, process and design activities. In a workplace setting, participants in design are part of a profession, and they act as voices of their profession in design. The heterogeneity faced by design can be, and has traditionally been, understood and managed in terms of mutual learning [8], negotiation [10], and similar concepts. Patients are not part of a profession, but more the central subject in a life changing process. Patients can be in denial, they can be very weak, they can be about to die, or in another “weak” state, in need for care. As objects of care it seems unlikely that they can cooperate in a traditionally staged participatory design process.

In this paper we aim to provide a new basis for understanding and staging cooperation among stakeholders in participatory design for therapeutic domains. We do so with inspiration from Strauss’ and co-workers’ concepts of trajectory and suffering. These are biographic concepts that provide a somehow operational understanding of the subjectivity of the patient. The claim we make is that such concepts are needed in order to see the patient as center.

2 Designing in therapeutic domains – three examples

To support the conceptual argument of the paper we introduce three design-led research projects in the therapeutic domains. Firstly, the adherence engineering project, aiming to develop means to ensure data quality in self-measurement in the unsupervised setting by collecting relevant context data [22]. Secondly, the neonatal intensive care-project, aiming to design infrastructures enabling equality between stakeholders - parents, health care professionals etc. - around the prematurely born child [14]. Thirdly, we look into the mobile anxiety therapy project, aiming to design a mobile tool to support cognitive behavioral therapy [6].

2.1 Adherence engineering: patients as *object* for intervention and control

The *adherence-engineering project* is introduced here as an example of engineering thinking, in relation to how patients cooperate in a health care situation.

Adherence is generally defined as the degree to which patients conform to the therapy, e.g. by taking their medication [24]. Measurement adherence is then defined as how the patient conforms to measurement guideline and instructions. Wagner et al. [22] address the challenge to support valid measurement of biomedical data in the unsupervised setting. E.g., when patients are asked to measure their blood pressure at home.

Blood pressure is an important indicator in many conditions, such as complicated pregnancies, and hypertension is, by itself, a dangerous condition leading to strokes etc. At the same time it is complicated to measure. The measurement is technically fairly simple, but the blood pressure measured is quite sensitive to how the patient is positioned, when they have eaten, been drinking coffee or smoked recently, or if they

are talking. Also, there is a white coat effect, which means that some patients have a higher blood pressure when getting it read in the clinic. A set of 13 guidelines exists, but all patients do not know them. Thus, while it makes much sense to let patients measure their own blood pressure (due to simplicity, economy, and white coat effect), it is hard for physicians to assess the quality of the data. In situations where blood pressure is an indication for intervention, e.g. medication for hypertension, the quality of data may be of less interest as long as the values are below the threshold. In many situations, however, more accuracy is needed. This leads to a wish for integrating measurement of the users adherence to measurement guidelines into blood pressure self-measurement devices.

Wagner [22] formulated a conceptual framework for adherence engineering describing adherence verifiers, measuring the quality of data by assessing adherence to guidelines, and adherence aids, providing feedback and guidance for the patient. Subsequently, prototypes, testing various aspects, were built. The sensor chair detected if patients had their back rested and legs not crossed. The audio classifier analyzed the sound near the device to detect if the patient was talking. Both these approaches worked well. On top of this an integrating framework for collecting data sources and giving feedback to the patient was experimented with.

In the measurement adherence project a major challenge for design seemed to be to get a sufficiently nuanced understanding of the therapeutic domain and the users/patients perspective.

The question is, however, if it is possible to develop this strategy to a stage where adherence is controlled completely. The main challenge is that brute force engineering is expensive and complicated. It would be necessary to track everything patients were drinking, their movement, etc, and that seems unfeasible for the settings where self-measurement of blood pressure is administered today.

An alternative approach discussed in the adherence-engineering project was to find a feasible balance between measurements and reliance on patients' abilities to follow guidelines. It was speculated that some guidelines were more essential than others and if those were adhered to, the rest would also be. However, many studies [e.g. 15] show that patients have difficulties understanding the medical rationale behind treatment or measurement they are expected to adhere to, and that they some times deliberately tamper with data, conditions for measurement, etc. for reasons that can be hard to understand from the rational point of view of engineering and control. Thus, it may be difficult to decide which guidelines would be good indicators of complete adherence, partly because this could depend on the patients' subjective experience of the whole situation.

The discussion above could lead to a negated approach disregarding technical adherence engineering. An ordinary chair could be painted yellow and placed in the outpatient clinic, or in the home of the patient, and together with the patient a narrative about blood pressure measurement behavior on the yellow chair could be created. This kind of adherence engineering would be based in patients' subjectivity, and would acknowledge patients' active agency rather than aiming to take full control of the patient through technology.

The reported difficulties in the adherence-engineering project illustrate that even in fairly simple situations, like blood pressure self-measurement, it is difficult, if not impossible, to make useful design based on the ideal of the patient as an object for control.

2.2 Care community: patients as an *object of care*

The neonatal case, *care community*, is introduced here as an example of cooperative care, and how heterogeneity can be addressed through a joint structure for care.

Neonatal intensive care is administered when children are born so early that they will not be able to survive in a natural environment. The child is placed in an incubator and controlled constantly. Prematurely born children are not fully developed, and therefore most often require careful diagnosis and case-by-case intervention. In many cases the child suffers from malformations of vital organs, etc. At the same time, the parents will be in a process of coping with the premature birth. Furthermore, the child itself needs close contact with the mother in order to develop emotionally. In this complicated picture, nothing is relevant without the survival of the child as a biological entity.

In the Italian context, studied by Grönvall et al. [14], parents were only allowed to be in the ward, and thereby with their children, for very limited periods of time every day. This limitation was due to the immature baby's need for being in the controlled environment of the incubator, and partly a concern for the parents who have the choking experience of expecting a healthy normal child and now becoming parents to an immature, ill, strangely looking creature instead.

In the design project, Grönvall et al. [14] developed a novel concept of care communities, embracing the heterogeneity of the situation around the prematurely born child, and they developed a vision and a number of prototypes of a system called Palpable time. This development was done in a cooperative design effort involving the researchers/designers, staff at the hospital and to some extent parents of prematurely born children. According to one of the participating pediatricians, the most revolutionary part of the project was the principle that parents, nurses and physicians could work together as a care community jointly aiming to save the child [14]. Thus, an important part of the project was about empowerment, in particular of the parents. An important aim was to change the power structures of the hospital, while not challenging the therapeutic regimen.

The Palpable time prototype was envisioned as an opportunity to create windows for cooperation between stakeholders in a system of configurable presence and absence. In these windows, everybody was thought to be on equal terms but in a way suiting each individual, profession or role. E.g. it was envisioned that the system could enable the mother at the same time to be intimately connected to the child through voice, heartbeat etc., and be absent enough not to be fully confronted with the clinical truth, that might be too unbearable.

The Palpable time prototype acknowledged the heterogeneity of perspectives on care. Parents coping with their new life situation and trying to stay in contact with

their child, nurses ensuring the continuity of care, pediatricians administering the therapeutic regimen, etc.

However, it can be argued that the ideas of the care community and Palpable time result in a limiting understanding of the central “stakeholder”, the child. Obviously, the child is unable to discuss the therapeutic regimen with the medical staff, but it may not mean that it should be understood merely as an *object* of care. While Grönvall et al. [14] carefully address the situation from the point of view of the parents within the therapeutic regimen, they do not address the subjective perspective of the child. The Italian medical perspective on neonatal intensive care is that the child should stay as much time as possible inside the “safe” environment of the incubator. In northern Europe the perspective is that the prematurely born should spend as much time in bodily contact with the parents, and parents are encouraged to spend as much time at the ward as possible. Which is better from a medical perspective is disputed. The interesting question is what would be best from the subjective standpoint of the child, at the specific point in time as well as in the lifespan of the child.

The care community project illustrated that design efforts focusing on the heterogeneity of a cooperative situation may be in danger of subsuming all perspectives under rational principles such as survival. Furthermore, it illustrates how the dominant perspective of care does not ensure an understanding of the *subjectivity* of the person being cared for, but rather reduces the person to an *object* of care. The child is center as an object, but not in center as a person.

2.3 Mobile anxiety therapy: patients *subjective incommensurability* with the therapeutic regimen

The *mobile anxiety therapy* project is introduced here to illustrate the relation between therapeutic regimen, therapeutic practice and life transformation.

Anxiety disorder is a widespread problem in western societies, between 15 and 25 percent of the Danish population will at some point in life develop an anxiety disorder [2]. Anxiety disorders can in some cases be invalidating, but good results have been obtained from using various forms of Cognitive Behavioral Therapy (CBT), with exposure as a central element [25]. However, the number of people suffering from an anxiety disorder means that many of the lighter cases never get treated, and some of the severe cases do not get treated due to the scarcity of therapist hours.

The mobile anxiety therapy project [6] was motivated by a wish to help people overcome anxiety in a more efficient manner. The aim was to develop a mobile tool that could support anxiety therapy. The researchers collaborated with therapists and patients¹ from a center for anxiety therapy providing a 3-month, full time program for young people. Typically, patients suffered from social phobia or agoraphobia. Early design ideas assumed that initial warning of the build-up of anxiety attacks provided

¹ For the sake of consistency over the three examples the client, or students in the anxiety program are referred to as patients

by biosensors connected to the mobile device [4], would be a great help. Technically, that turned out not to be feasible, but fortunately it also turned out that anxiety is a condition that it is easy to learn to sense and measure. This led to the design of a mobile application that was much more closely related to the existing practice in the anxiety therapy center.

Designers cooperated with therapist and patients to learn about anxiety and about the anxiety program. Together they developed ways to integrate therapeutic instruments into the mobile device. Central elements included a version of a CBT five column scheme for constructing alternative thoughts; an anxiety diary; plans for exposure exercises, including encouragements to do them; means of relaxation including music; and reassuring sentences. Most of the actual contents for these elements had been constructed by each of the patients as part of the therapeutic program. Thus, the application became a tool to bridge the gap between the clinical setting of the program, and the non-clinical situations outside in the world where anxiety attacks normally occur.

An important issue in the mobile anxiety therapy project was to make sure that patients were not hurt by the design activities, e.g. by being overly exposed to social situations during design workshops. The solution was to involve patients who were in the final stage of the program. In that way, design activities simultaneously became therapeutic activities in the sense that they exposed patients to new social situations and provided situations where they were forced to talk about anxiety with “strangers”. Thus, cooperative design was subsumed under the therapeutic strategy. A further advantage of involving patients at the late stage was that they had developed an awareness of the process of change they were undergoing.

Two complementary or conflicting perspectives on the mobile application emerged in the project: as an addition to the therapist’s arsenal of tools, or as an instrument for patients’ to expand and relate therapy to their lives at large. The mobile application became a boundary object [19]. It turned out that these conflicting perspectives on the application were instances of a more general tension between therapy and life transformation. For the therapist, anxiety could be cured through the therapeutic program’s strategy and practice. For the patients, life was in transformation, and therapy represented change and a challenge to the life they knew, as well as a safe place in life. An example of this tension was the various forms of safety behavior enabling patients to cope with daily life but somehow leaving or even enforcing anxiety, e.g. by avoiding certain situations or places. An important part of the therapeutic strategy was to help patients break out of safety behavior, and at the end of the program staying attached to the program and the center for anxiety was understood as a form of safety behavior by the therapeutic regimen. From the point of view of the patients, this contact was seen as an enhanced possibility to manage life. Thus, the design project uncovered a possibly deeper conflict between the perspective of life transformation held by the patients, and the perspective of the therapeutic regimen curing anxiety disorder in 3 months. Understanding this conflict is also key to the design of aids to keep doing the exposure exercises, leave the safe harbor of therapy, etc. To better understand this tension, a concept of patients’ subjective life transformation, i.e. a biographical concept, is needed.

When patients enter the anxiety program, they have most often built an identity as someone suffering from anxiety. Through the program, they change that identity. The program, when successful, is a turning point in their lives, but the program is still just an intermezzo. Before and after, they depend on their own strategies for coping with the world as possibly anxiety provoking. They will need to integrate themselves and their new strategies as not suffering from anxiety into their world. This trajectory of patients' changed perspective points to how awareness of self changes from possibly non-anxious, through anxious, through the therapeutic program as someone working full time to recover from anxiety, to the after treatment situation of being (hopefully) a post anxiety recoverer.

Recovering from anxiety includes more than conforming to the therapeutic program. While the therapeutic regimen is based firmly in cognitive behavioral therapy, the trajectory of the recovering person across various contexts would be based more loosely in that regimen, and could also include, e.g. maintaining elements of safety behavior at a non-detrimental level. From the point of view of patients, it seemed as a possibility to transfer insights and new practice from the therapeutic program further into life outside therapy that was the most important aspect.

The mobile anxiety therapy project shows that fundamentally different processes overlap in therapy, and that in order to design it is important to understand both sides of the cooperative arrangement. As the concepts of therapy are very strong, equally strong concepts of subjectivity of patients are needed.

3 What is the problem and why do we need a new concept

The above three examples show, in different ways, how systems design is problematic if patients' subjective perspectives are not taken into account. Subjective perspective is in this context not only a matter of understanding the interests of patients and prioritizing what is best for them. The subjective perspective is how patients understand, feel and relate to therapeutic intervention and technology in the complex context of their own lives.

The adherence-engineering project provides an example of how the conceptually simple idea of technical control becomes impossible to realize if it is not paired with insights into the patients' perspective.

The care community project example provides an example of a rational perspective on care and survival that does not take the subjective life of neither child nor parents into account as primary concerns.

The mobile anxiety therapy project provides an example of the tension between therapeutic regimen and patients' life management, as it surfaced in the course of cooperative design.

3.1 Stakeholders

The three cases introduced above, illustrate several distinct types of stakeholders and processes. In the adherence engineering case, the patients are immediately affected by

the introduction of a new device for blood pressure self measurement, and successful design is highly depending on a clear understanding of the patients' perception of the measurement situation. The possibility of getting more reliable measurements obviously makes the job easier for health care professionals also. Self-measurement can be a case of a well-known routine for some patients, but for others it can be part of a more critical sickness situation. It may be helpful to understand both.

The neonatal intensive care case presents another level of complexity. The prematurely born is affected and basic survival is the most important goal. For the parents having a prematurely born child in intensive care is a serious life-transforming crisis. For the healthcare professionals, however, working for a prematurely born to survive is a recurring standard task. Their quality of working life will be affected by changed technology and organizational concepts, and they go through a process of change across their experience of hundreds of cases.

In the anxiety therapy case, it is patients' process of recovering from anxiety that is primarily affected, though the working life of the therapists may change too. What makes the anxiety case different from the self-measurement case, is that anxiety therapy does not become routine. It is a life transforming process per se, and every step is a challenge for the patient. In order to design for this case, an understanding of the therapeutic regimen is important, but it is equally important to be able to address the relation between the therapeutic regimen and the actual change processes going on with the patients.

3.2 Processes

How can patients and relatives be involved in design, when they are undergoing critical life transformation? In such situations, involving users means that we will be involving them in a design process that addresses a process they are themselves in the midst of, and that design may intervene directly in the transformation of that users' life. The stakeholders in the three cases are involved in a multitude of processes that are overlapping and intertwined, but not necessarily comparable or commensurable. With respect to participation, participatory design has a concern for the active involvement of stakeholders, in particular end-users, in the process of design [3]. Furthermore, the three examples show that the active, co-determinate, engaged involvement of patients in the therapeutic intervention is also an important issue. It seems that that the active involvement in therapy may be a precondition for involvement in design. From the above examples we can identify at least four types of process relevant for an understanding of the involvement of users.

The IT-design process is the change process organized by systems developers leading to the introduction of new IT-based artifacts. The process may involve actual users or it may be driven by an idea, or specification. The three examples illustrate that design is not going on in an otherwise frozen world, and that other processes are important to understand in order to do design. In some cases the design process occurring in practice can be contrasted to idealized ideas, e.g. in the form of methods, of how design should be undertaken.

The therapeutic intervention process is the actual process in which patients receive therapy and care in order to recover from, or get to manage their illness. The actual course of therapeutic intervention is the realization of a therapeutic regimen, but implemented by the actual therapist and including exceptions, method mix, etc. These processes of therapeutic intervention, in turn, evolve over time.

The therapeutic regimen is the principles and procedures of ideal therapeutic intervention. The historically evolving guidelines condensed from experience of the profession, and based in medical research. The CBT program for anxiety, or the 13 guidelines for blood pressure measurement are components of therapeutic regimens.

The life transforming process of illness and cure is the process patients undergo as whole human beings. The baby's struggle for survival, recovery from anxiety, etc. This is a subjective process.

While the relation between design on one hand and the dynamic relation between therapeutic regimen and therapeutic practice on the other is potentially complicated in the same sense work-oriented design always is, it is the relation between patients' life transformation, and the other processes that appears hard to address in the three examples. The deeper layers of patients' life transformation seem incommensurable with the other processes.

3.3 Cooperative design

Cooperative or participatory design of IT focuses on the involvement of stakeholders in the process of design; in particular those stakeholders that are directly affected by the new systems, and in particular those who are most often left out of the process.

The early trade union projects realized that technology was not neutral, and that workers therefore needed their own experts, to ensure that their perspectives were brought to the table in the power struggle with management [3]. Thus, Ehn and Sandberg [10] proposed a model for systems design as negotiation between workers and management.

Subsequent projects, e.g. the UTOPIA project [3], learned that workers were unable to make sense of the systems models provided by their own experts. Non-IT professionals were unable to translate formal systems descriptions into an understanding of how work would be in the prospective work arrangements. Therefore, new types of design representations such as organizational games [9], and Mock-ups [11] were invented to capture the heterogeneity of perspectives on technology and to enable to participants to cooperate across professional differences.

Mutual learning became a central concept in organizing cooperation across the heterogeneous perspectives, knowledge and competencies of interested designers and stakeholders [8].

Thus, participatory design envisioned and practiced design as a *rational discourse* among the interested parties. Not necessarily formalizable and rationalistic, but happening in a room where perspectives are sharable through language and design artifacts (prototypes, etc). In the three examples, involving patients in the (rational) discourse of participatory design was a challenge, as they were weak, choked, fragile etc.

3.4 Care, rationality and rationality of care

In discussing cooperative design, [7] take up Noddings' [17] concept of care rationality as a counter point to technical rationality. The concept is relational and reciprocal, based on the caring persons own experience of being cared for, and it is concrete, situational rather than formal and abstract. In the concept of this paper, it is a limitation that Noddings' [17] argument is mostly based in philosophical ethics that seems to remain quite abstract. A more concretely based alternative is provided by Wærness [21], who discusses rationality of care from a sociological perspective in an effort to make visible the invisible work of care traditionally done by women outside the realm of scientifically based, controlled procedures. The rationality of care is understood as opposed to scientific rationality, and is based more on intuition, experience and improvisation than on procedures and formal education. In the context of the three examples, a focus on the rationality of care can provide new insights.

In the adherence-engineering project, it seemed to be a goal to avoid caring rationality. The project represents a scientification of a domain, the home etc. that was otherwise a domain of care. In the mind of the engineer, the various practices expressed by nurses, e.g. tugging the patient in with a blanket if the measurement is too high and then repeating it later, seemed like a kind of witchcraft that should be avoided.

In the neonatal intensive care project, the neonatal intensive care ward was a kingdom of scientific rationality. This was the background for one of the pediatricians stating that the most ambitious part of the project was not the incubators based on smart materials and non-existing sensor and actuator technology, but the very concept of a care community. Probably because he realized that care community implies an acknowledgement of the rationality of care.

In the mobile anxiety therapy, it was a clear dynamic between scientific and caring rationality in the way therapy was carried out. CBT itself is a paradigm relying on well-described procedures, but in the practice of the anxiety program a lot of improvisation, method mixing, individual adaptation etc. was seen.

However, the concepts of rationality of care (Wærness) and care rationality (Noddings) both tend to understand the cared for person as an object. The actions, knowledge, perspective, etc. of the caregiver is what is central to understand. While both authors emphasize reciprocity in care, and the caregiver's sense of the needs of the person cared for, this is still seen from the caregiver perspective. Thus, the person being cared for is kept in the position as *object of care*.

While the two concepts provide a more complete picture of therapeutic work and the relation between care and therapy on one side and the patient on the other, they at the same time indirectly reveal that the subjectivity of the patient becomes a residual category. Patients seem only to exist through their reflection through therapy and care. Thus, a set of concepts setting patients at the center, are needed.

4 Suffering – an exemplary biographic concept

The concept trajectory was coined by Strauss and Glasser [20] in the context of the dying person. It aims to describe the specifics of the total situation of the dying person; the biological process of bodily decay, and the unplanned process of becoming dead, the un-orderliness of the surrounding social context, the bewildered state of relatives, etc. Riemann and Schütze [18] argue that trajectories, in the Strauss sense, are about suffering, and the whole context of the suffering person. Obviously, the concept of trajectory is a specific grounded theory based on the studies of dying and of chronic illness [18]. Therefore, the specific models of e.g. the stages of chronic illness trajectories may not be found in e.g. the context of rehabilitation. However, it is as a biographic perspective centered with the suffering person, the concept trajectory brings a new understanding to IT-design. It is not just a matter of viewing the situation from the point of view of various stakeholders including the patient. It is a matter of realizing that the rationality of design and of work, including medical work, does not apply for the suffering person as such. Riemann and Schütze [18] argue that the concept of biographical trajectory can be somehow generalized from the sociological analysis of suffering.

In this section we introduce Anselm Strauss' and colleagues' [18, 20] concept of suffering and trajectory as a basis for a discussion of subjective and biographic perspectives in design. By aiming for a biographic approach, we want to emphasize the concrete subjectivity played out through actual events in the course of life. A biographic perspective on subjectivity emphasizes process and change as opposed to more static aspects such as identity or personality. That is not to say that personality and identity are not relevant aspects in understanding subjectivity, though. We mainly build this discussion on Riemann and Schütze's account.

“We believe it is necessary for an understanding of suffering to leave the paradigm of intentional social action, and to start conceptually from social processes of "being driven" and losing control over one's life circumstances.” [18 p.336]

Thus, the concept of suffering points to the fundamental incommensurability between the suffering person and healthcare professionals, designers and others. It is the subjective standpoint of the patient in the trajectory of illness. Suffering is constantly changing and cannot be rationalized. Compared to Noddings' [17] and Wærness' [21] perspectives on care, the biographic concept of suffering maintains a focus on the suffering person where Noddings proposes a universalized philosophical concept of a non-universal relationship, and Wærness is mostly occupied with a sociological analysis of the invisible work of the caring person. Suffering, in the case of the dying person, implies the dissolution of rationality and personality. Thus the concept of suffering provides an extreme biographic perspective. Thus, it can serve as a Leitmotif for the development of a biographic perspective as a basis for new ways of understanding the involvement of patients in cooperative design.

Studies in computer supported cooperative work have addressed therapeutic domains, often aiming for general domain sensitivity rather than narrow implications

for design, and pointing to the un-orderliness in contrast to formalized structures in organizations. In particular the works of Strauss and colleagues have been influential. For example, Graham et al [14] discuss how Strauss' concept of trajectory can be operational for a design-oriented understanding of the healthcare domain. However, they take a mostly organizational, objectified view in their analysis of ethnographic data, and seem to understand the concept of trajectory in a less empathetic and subjectivist way. For them it is mainly a correction to traditional bureaucratic models of the organization of human behavior, understood as a frame for describing visible behavior rather than a model for understanding various fundamentally different subjective backgrounds for action and participation.

In their book, "Technology as Experience", McCarthy and Wright [16] introduce the subjectivist concept of "an experience", in the broader conceptual context of "felt life". While their focus is on the singular events rather than on trajectories, their analysis of four threads of experience, six ways of sense making etc. provide specific handles for an understanding of concrete, felt life with technology or other arrangements that would complement the Strauss inspired, biographic concepts. could be a useful complement to the concept of suffering and of trajectory in actual analysis and design. The work reported by Wallace et al. [23] provides an interesting example of biographic design, based in critical design and aesthetic experience. They worked together with one couple, where the wife was suffering from dementia, to produce jewelry that could help maintain memory and sense of self for the wife.

4.1 Biographically informed design alternatives in the three projects

Through a biographic perspective inspired by Strauss concept of suffering, a number of shortcomings in the three projects can be discussed and insights into alternatives can be obtained.

In the *adherence engineering* project patients were involved through studies of the settings for blood pressure self-measurements. The typical inaccuracy of measurements was studied through observations and interviews. However, it was not at all made clear through the framework developed in the project [22], how to create a balanced combination of technical adherence aids and verifiers and means of adherence not based in technology. An approach could be to study specific groups of patients at a much more detailed level. Aarhus and Ballegaard [1] report on a broad range of studies of how patients managed illness with technology in their own homes, and they point to difficulties in integrating these activities with other activities in the home. As one example they point to issues of visibility of the health technology. Aarhus and Ballegaard [1] further point to examples of how pregnant diabetics understood blood glucose measurement in terms of connectedness with their child, and not in terms of technical measurement. Thus, a next step in building an adherence-engineering framework could be to address bio-medical self-measurement in the context of specific patients' illness trajectories [20]. For example, for patients in the phase of denial, the technical adherence aids proposed by Wagner [22] would not be effective. A consequence of such a biographic approach would be to understand bio-medical measurement as boundary objects with one meaning in the

clinical domain and another meaning in the context of illness trajectory. (Tactics 1, 2 and 5 below.)

The *care community* project adopted a stronger care perspective. At the same time a strong focus was placed on smart materials for preventing pressure, etc. While the researchers in the project felt that contact between mother and child was valuable, the scientifically based therapeutic regimen of the hospital forced them to address that value through technical means. The scientific rationality of medicine and technology ruled. With a biographic concept like suffering it is possible to generate a version of the child's subjectivity and trajectory, and possibly do the same for the parents. While it is impossible to interview the child in neonatal intensive care, it is possible to observe them across their life span. It is indeed possible to get subjective accounts of how the time in intensive care affected the person later in life. While this may be rationalized in terms of attachment theory, the important point is that the biographic perspective of the suffering child and its trajectory into, and in, life would have helped the researchers in the care community project to become more insistent about ways to reunite what medical technology had separated. And it would have provided researchers with a critical stance towards their own technical solutions. This could have powered an insistence on moving the child back with the parents when at all possible, and then develop technology that could transfer the protection of the incubator out of it. (Tactics 1, 2, 4 and 5 below.)

In the *mobile anxiety therapy* project, patients were involved actively in design activities. The therapists had a very well defined vision of the therapeutic regimen that would realistically help patients into a normal life. The basic rationale of this regimen was that patients should obtain control of anxiety, and consequently of their own lives. It became clear, however, that the patients did not share that vision. The patients took off from their positive experience with specific therapeutic measures, and general ideas of what would be nice to have. In general they did not focus on how various elements in a tool would support the therapeutic regimen of CBT within the limited time of the therapeutic program. The researchers (who also designed the prototypes) feared that patients could be harmed by design activities. Therefore, they proposed that design activities should double as therapeutic activities. Design should be subsumed under therapy. While this was a safe strategy, it also limited the possibilities to think beyond the existing therapeutic regimen. Design adopted the limitations of CBT. The biographic perspective of suffering and patient trajectory would have been a useful counterbalance to the CBT perspective. With this as a central part of early analysis, pragmatically subsuming design activities under the therapeutic strategy would not have been a Trojan horse² for the delineation of therapy inherent in CBT. It would not only have been possible to reflect actual practice, as opposed to the idealized therapeutic regimen, in design, but it would have been possible to think beyond existing therapeutic practice, designing for patients trajectory. (Tactics 1, 2, 3, 4 and 5, below.)

² Bertelsen [5] analyses systems development methods and tools as Trojan horses for a world-view.

4.2 Biographically informed design tactics

Based on the discussion in the previous section we extract a number of possible tactics, informed by a biographic perspective, for the design of IT support in therapeutic domains.

Tactic 1: Take a biographic perspective, inspired by the concept of suffering, on stakeholders in design. Use this perspective to help understanding patients as interested collaborators with a specific type of agency (of suffering) rather than objects of therapeutic intervention. Do not assume that patients share, and act according to the rationality of therapy - or any rationality at all.

Tactic 2: Consider trajectories of life and illness, including life before and after therapy, as the basic units of analysis. Rely on personal accounts from patients and former patients.

Tactic 3: Relate product design activities to the distinct processes of therapeutic regimen, therapeutic practice and patient's trajectory when organizing design activities.

Tactic 4: In the practical involvement of patients in cooperative design, it can be necessary to subsume design activities, such as idea generation or prototyping, under therapeutic activities, e.g. to avoid harming patients. In doing so it is important not to limit design by conceptually subsuming it under the therapeutic regimen.

Tactic 5: Acknowledge design that contradicts or transcends established therapy.

5 Discussion

Based on three projects, we realized a need for a stronger set of concepts that could promote the voice of patients in design. As an answer to this need, the idea of a biographical perspective inspired by Strauss and colleagues' concepts of illness trajectory and suffering was introduced. This perspective was supported through a critical discussion of rationality and care.

The idea of the biographical perspective was validated through the identification of shortcomings in the three reported projects and exemplification of alternatives based in this perspective.

The subjectivism and critique of rationality brought about by the biographic concepts, not only relate to participation in design, but it also points to engaged cooperation, by patients, in illness and therapy more generally. This attempt to place patients at the center of agency is needed in relation to design. There may, however, be limits to equality in therapy when issues such as accountability, responsibility and professional judgment are taken into account. In practice many situations may not call for more active engagement by patients. Thus, the aim of this paper has not been to eliminate the perspective of professional healthcare workers.

The argument of the present paper has been taking of from examples in health care, emphasizing patients' inability to participate in rational design discourse and negotiation. It may make sense, however, also to consider if cooperative design in general is facing the same kind of difficulties. Hopefully, the way the concepts of suffering and trajectory facilitates biographic or subjective perspectives in therapeutic

domains could inspire the further development of perspectives on participation and cooperation in other areas such as civic engagement.

Future work could include experiments with a set of operational guidelines for biographically based design. Such guidelines may be tried out in the context of the continued adherence-engineering project.

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