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DENMARK

The Question Concerning Narration of Self in Health Informatics

Botin, Lars

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Lars BOTIN

Aalborg University, Denmark

Abstract. Narration is central, even crucial, when it comes to embracing the whole individual, continuity of care, and responsible (ethical) handling of the technological construction of the self that takes place in health informatics. This paper will deal with the role of narratives in the construction of health informatics platforms and how different voices should have space for speech on these platforms. Theoretically the paper takes an outset in the actant model for narratives by the French-Lithuanian theorist of linguistics and literature A.-J. Greimas and post-phenomenological readings of human-technology interactions. The main assumption is that certain interactions and voices are absent from the construction of health informatics platforms, because regarded as outside the text of computational and medical practice and expertise. This has implications for what concerns meaning and understanding regarding both the actual users (physicians and medical staff) and excluded users (patients and citizens).

Keywords. Narratives. Self. Health informatics. Value Sensitive Design

Introduction

This paper will deal with the importance of narratives and the understanding of narratives in relation to construction of meaningful continuity of care and how selves are co-constructed through language embedded in technologies. This is made in order to discuss 'how can the role of the citizen and the patients be enhanced in complex health IT contexts'? It is the assumption that meaningful continuity of care is hindered and to some degree even prevented by the lack of different narratives in health informatics, and it is not considered how we co-construct ourselves together with technology. This means that we are and remain unaware and unconscious of the role played by technology in moulding ourselves in its picture. The French philosopher Jacques Ellul was of the opinion that technology determines our beings, feelings and behaviours and there is no escape from this reality. He writes: "The new man being created before our very eyes, correctly tailored to enter into the artificial paradise, the detailed and necessary product of means which he ordains for himself – that man is I" (1). We have become perfectly tailored components that as means fit neatly into the technical system that has a determined end, e.g. the artificial paradise.

This paper is not a technological determinist or dystopian contribution to already existing dystopias' of the 20th century like Oswald Spengler (2), Jacques Ellul (1), Martin Heidegger (3) among many, but rather an attempt to describe the overall inappropriate handling of language and language-systems in health informatics. The

language-system in health informatics is characterized by a one-dimensional focus on standards (4), which certainly is needed in order for systems and people to interact, but as if one-dimensional on the premises of technology, then we lose the full body of the patient/citizen and that of the professional herself. It is important to notice that it is not only the patient/citizen who is moulded, but also the actual user of the technology, e.g. physicians and medical staff who are transformed into 'one dimensional man' (5).

Technology is not vicious, anti-human or intentional on its own, but integrated part of the construction. Our selves are co-constructed with technology, where a certain kind of symmetry in between humans and technology are at stake and performed (6). Intentionality resides in both humans and technologies and we should be careful when dealing with the intentionality of health informatics, because, as it is for now, striving towards *efficiency, efficacy* and *effectiveness* controlled by instrumental and mechanical rationality. Ellul saw this determination layered within technology and could not find any escape from final 'technification' of humans and society, where humans are treated as means to an end in a chain production perspective.

On the other hand the American feminist and STS researcher Donna J. Haraway wrote the Cyborg Manifesto in 1991 and in it she foresaw quite a lot of what has happened within information and communication technology, and even though that the following quote might seem gloomy then Haraway actually greeted the coming of a new post-human age wherein a new type of humanity would prosper thanks to our interactions with machines and technologies: "Communication sciences and modern biologies are constructed by a common move – the translation of the world into a problem of coding, a search for a common language in which all the resistance to the instrumental control disappears and all heterogeneity can be submitted to disassembly, reassembly, investment and exchange…The world is subdivided by boundaries differentially permeable to information. Information is just that kind of quantifiable element (unit, basis of unity) which allows universal translation, and so unhindered instrumental power" (7). It is inevitable that technology will have an increasing and decisive importance in relation to how we as humans become, but this constant and dynamic becoming is not determinate and final. It is unpredictable and beyond our imagination, which means that we have to construct meaningful and responsible frameworks for handling human-technology interactions and associations where values and norms for what is means to be in these interactions and associations are explicated and activated.

In this perspective it seems as if health informatics is 'one dimensional' in its mechanical and instrumental rationality. Health informatics should be efficient, effective and effectual, but also embracing other *'e's* like *engagement, enactment, embodiment, empowerment, emancipation, empathy* and *enhancement* (8) in order for it to become multi-dimensional and *truly* representative for both medical staff and patient/citizen. In the following I shall address how the narration of the technological self can be constructed in health informatics and furthermore how context sensitive design based on values, norms and design criterions is possible in the construction of multi-dimensional man.

1. The self and health informatics

Health informatics is ontologically and epistemologically tied to what it is made of, i.e. health and informatics. Health is in this perspective human matter and informatics

technological matter. Health is subjective, emotional and bodily, whereas informatics is objective, mechanical and cognitive. This might seem as a dichotomy, but of course there are innumerable overlaps, connections and dialectics. We cannot separate subject from object, emotions from mechanics and/or bodily perception from mental cognition. Nevertheless there is a tendency of such distinctions, which is certainly not new – it has been going on ever since René Descartes separated the body from the mind in the 17th century – and despite courageous attempts in the 19th and 20th century to reunite body and mind then the distinction is still at hand. Medical staff is torn in between the two world-views (ontologies) as it is supposed to care for the health of the individual and maintain the authenticity of the self, and at the other hand account for the efficacy of cure, and maintenance and efficiency of the system. The latter mainly made through proper information systems. I shall return to the inappropriate focus on optimization of efficiency, mainly in a economical perspective, later in this paper.

For now I shall introduce to an actant/communication model, which could serve as exemplary sample of current problems in health informatics platforms that seems to prioritize, in an asymmetrical and inappropriate way, the objective, mechanical and cognitive on behalf of subject, emotion and body.

The French-Lithuanian theorist on linguistics and literature A.-J. Greimas' dualist actant model (9) concerning the construction and dynamics of a narrative, provides us with an understanding of current problems for what concerns communication and interaction in between doctors and patients.

Sender _Health care system_		Object _Cure/Care_		Receiver _Patient/Citizen_
Assistant _Medical staff_		Subject _Citizen/Patient_		Opponent _Health Informatics (?)_

Fig. 1: Actant model. After Greimas; 1966/1990

The 'assistant', who is supposedly, medical staff, have a certain picture of the individual that sits or lies in the clinic. They see her as a patient with a record related to sickness or/and injury. This record is told in objective medical language and layered within ontology and a system, which is literally and linguistically closed to the 'subject' and the 'receiver', e.g. the individual. The 'subject' as a citizen has a different narrative and wording, and the story often begins well before showing up in the clinic and/or the hospital. The perception and conception of the situation is often filled with doubts and worries that remains inaccessible to the narrative of the doctor, at least if we consider how ontology of health informatics is considered through SNOMED or similar tools for handling the complexity of health informatics in hospitals on a global level. The 'sender' and the 'assistant' may have all good intentions (and they have) to produce cure and care to the 'citizen/patient', but the problem is that technology may show as mediator of friction and opposition. The reason why is that it does not manage to cope with the lifeworld of the 'citizen/patient' and furthermore seems to hinder acts of empathy, empowerment and emancipation in relation to the medical staffs itself.
Of course this need not be the case, and health informatics is not in a position of friction and opposition per se. Actually it is often the physical and/or mental condition of the citizen herself, which causes friction and opposition. In other cases it may be the physician that changes role in the model and through a paternalist and commanding

attitude becomes the opponent to the autonomy of the citizen. This possible paternalist and commanding attitude of medical staff and of the health care system is readily supported by the health informatics platforms that are constructed in order to facilitate exactly this attitude. The autonomy and authenticity of the citizen/patient is not safeguarded in this regard, and if the individual is considered then it is overly in regard to safety of data in relation to integrity of privacy. It is obvious that health informatics as a tool should support practices of medical staff for what concerns cure, administration, workflow, safety and alike, but it is as well needed that information systems are considered as health and care technologies that assures/cuddles the maintenance of self and authenticity. In order for this to occur there is a need for a complimentary approach to health informatics and communication, wherein is present possibilities and potentials for authentication of selves, both that of the medical staff and the citizen/patient. In this way health informatics would escape the classification of opponent/alien to the self of the citizen/patient. The question is how this could be made?

According to the Greek philosopher Aristotle a narrative consists of a beginning, middle and an ending (10). It is that simple, or seemingly it is. Because where do things begin, where is the substance (the corpse) and when and where does it end? It is beyond doubt that narratives are interpreted in very different ways by citizens/patients and medical staff/health care systems. Life itself and the the life of the self begins, it evolves and it ends. Birth, lived life and death. This is also in the numbers of medical records, but exactly numbers. When we meet the health care system we carry our narratives, which is made out of myriads of folds (11, 12) and stretched out in between life and death (13). Lying on the couch we re not a 'case' or a symptom, that is just part of us in the given situation, but rather the occasional and situational carrier of something. It is this something, which is recorded in the system and what is left out is the core or the actual 'thing' – the person/human. What is layered in the system and in the narrative of the system is a bunch of 'somethings' that do not necessarily depicts or tells the story of the person, or make a representation of the self of the individual lying on the couch. At the same time it is obvious that these 'somethings' are co-constitutional of our beings and necessary elements in the narratives of our selves.

2. Context Sensitive Design in Health Informatics

There is no existential essence of the self, as continental existential philosophy would have it, but rather a multi-facetted crystal, where planes and sections are broken in different ways, and representations and meanings change as we turn the crystal. Currently health informatics is in search for the essential technical core of the citizen/patient as opponent to the impossible search of the individual for an essential human core. Both searches are out of line with the actual reality, which consists of a myriad of folds (11, 12) and thousands of plateaus (12). This is the actual context (reality) of which citizens/patients and medical staff is integrated part together with technologies. In order to arrange and manage folds and plateaus we have to address the design process with sensitivity, which according to the Dutch philosopher of technology I. Van de Poel should be layered within values and norms, e.g. value sensitive design (14).

Value sensitive design (VSD) has been around for the past ten years and mainly in a Northern European context. VSD takes an outset in ethics and morals wherein we ask ourselves what it means to be human and how we should interact with each other and

the world. Technology is, as we have seen, integrated part of this interaction and not an isolated object without any sort of intentionality. This means that the norms that can be explicated are not exclusively human in a conventional sense, but co-constructed and constituted with technology.

Values	Autonomy Health
Norm	Co-construction of Self
Design criterions	Citizenship and self determination — Technologies of the self

Values	Autonomy Health
Norm	Multiple Narratives
Design criterions	Everyday life language and standards — Communicative action

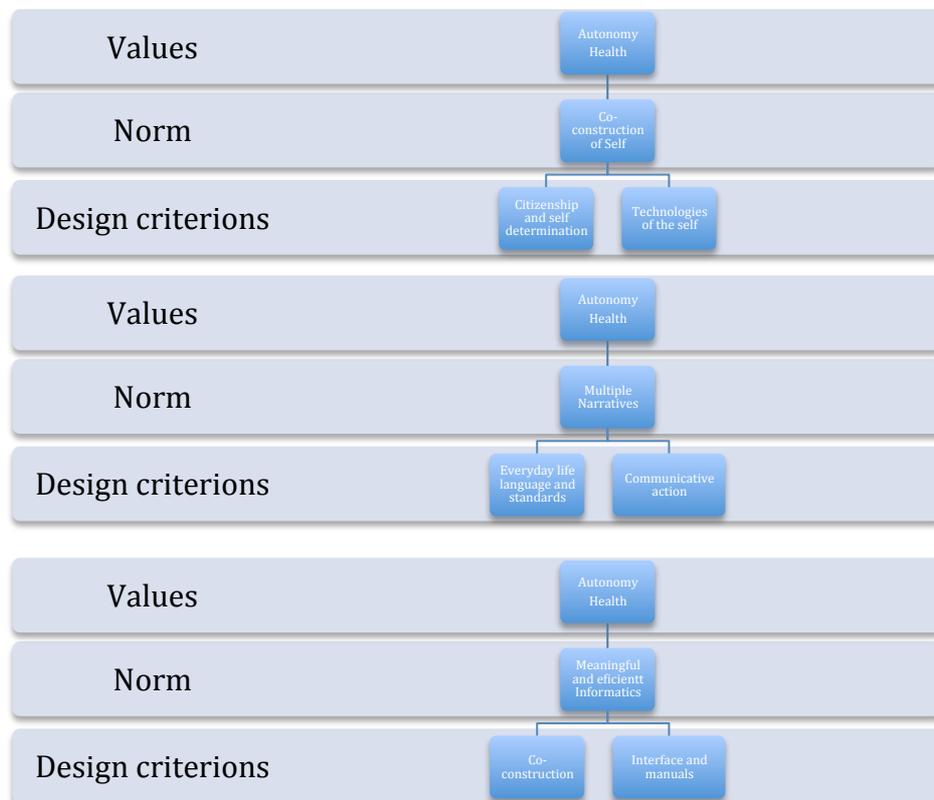| Values | Autonomy Health |
| Norm | Meaningful and eficientt Informatics |
| Design criterions | Co-construction — Interface and manuals |

Fig. 2: Value sensitive design. After Van de Poel; forthcoming

In the hierarchical tables above, which are exemplary, I have addressed autonomy and health as values. Other values, like utility, precaution, justice, inclusion, are as relevant and could be applied in the analysis of value sensitive design. The same thing goes for norms, but in this case they are closely tied to the main discussion of the paper: narration and self in health informatics. The design-criterions are requirements for guidelines that should direct construction of health informatics, i.e. have direct impact on ontology and architecture of the actual design.

3. Perspectives

One possible way to escape alienation and exclusion is to educate the medical staff to see health informatics as constituent for construction of self, and again, both that of themselves and of the citizen/patient. A close look at the medical curricula in a Danish context (4 medical educations) shows an alarming absence of training and education in health informatics, and very little reflection on self and the importance of narratives and language. The recommendations of this paper is to create platforms for health informatics in medical educations, and furthermore to address the importance of

language, self and narration in the construction of health informatics. This means that medical staff should receive adequate and appropriate training and education in health informatics. Not in order for them to be able to program and develop technological platforms and solutions, but in order for them to be on a level to understand the architecture of health informatics (ontology, terminology, content, construction, format and outline) in order to interact on both an operational level and on a design level. The latter because their experience and training in the *art of medicine* (4) is needed in order to assure axiology in the architecture (ethics, aesthetics and thought collectives/paradigms). In the perspective of this paper this means that the *e's* of effectiveness, efficacy and efficiency has to be complemented by engagement, enactment, embodiment, enhancement, emancipation, empowerment and empathy, which are all *e's* that take their rationale in axiology (8).

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