

Towards Citizens' Empowerment with the Coper-pilot

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Abstract. According to WHO, 50% of chronically-ill patients do not follow treatment guidelines. One way to promote commitment to care and treatment is empowerment. In this paper, we present an idea about an empowering process that 1) awakes the citizen to see that health-related change is needed (*a fracture*) and 2) brings up the motivation to achieve that change (*a goal-oriented action*). This process may be supported in different ways, for example with information technology. This supportive tool, however, needs to focus on the needs of citizens, not on the needs of healthcare professionals, in order for it to be truly empowering. Thus, a citizen-centric approach is needed. In the Coper-pilot, a sub-project of the EU-funded Pump-project, this approach is adopted. The concept of Work Informatics is used as a framework for research, with the goal of creating citizen-centric information systems that support goal-oriented actions of citizens to promote patient empowerment.

Keywords: Coper, Citizen-centric, Motivation, E-health, Cardiac patient

1 Introduction

Modern health care is facing different challenges, or should we say problems. It is worth of notion that already over three decades ago the problems were almost the same. Already in the 1980s, Andre De Vries [1] was pointing out problems of healthcare: problematic relationships between patients and doctors, patient anxiety and revolt, dehumanization of medicine, societies having financial difficulties with healthcare expenditures, over-treatments, problematic healthcare distribution etc. De Vries was pointing out that people should take responsibility of their own health, as they are free rational agents of society. However, before people can take the responsibility, there are some requirements to be fulfilled. First, there must be patient autonomy. Without autonomy of the patient there obviously cannot be responsibility. Secondly, people must have a right for care and treatment before they can be held responsible for their health. Third, people must have information. Without understanding one cannot have plausible responsibility. [1] Today, we are facing similar problems to those described by De Vries, and we must bring citizens to be active actors of their own health and well-being. Thus, we must change the approach to how health and illness is faced; those cannot be put behind the veil of medicine if the change is wanted.

In this paper, we have three major points to present. First, the premises of citizen-centric approach are introduced as a justified and solid ground for altering the current situation to a better one. The definition of health as “*homelike being-in-the-world*” by Svenaeus and “*Salutogenesis*” and “*Sense of Coherence*” as a view of well-being from Antonovsky are used as a new approach in the on-going Coper-pilot. [2] Secondly, the Coper-pilot and Work Informatics approach are presented. The Coper-pilot is a citizen-oriented project that is using the concepts of Svenaeus and Antonovsky as a starting point. The Work Informatics approach is used as a development framework that emphasizes social aspects of using information technology. Thirdly, the terms *fracture* and *goal-oriented action* are introduced. These two terms are used to bring forth the multi-dimensional aspects of patient motivation when trying to achieve patient commitment to care and treatment. Fourth, we will present some observed needs of citizens, especially concerning e-health solutions for citizens. The focus is on citizens with some cardiovascular disease, the target group of the Coper-pilot. At the end, there are some conclusions.

2 Ideological Background

The ideological background is based on the problem that WHO has presented; 50% of patients in Western countries do not follow treatment guidelines they have received [3]. This is clearly a problem and it is not solved with more direct orders from doctors or by adding more medical guidelines. We must see the needs and experiences of the people and figure out the way to increase the willingness of those people to commit to their care and encourage people to take an active role in improving their own health and well-being. In order to be able to do this, we must have some understanding and definition about health and well-being in the context of individuals. We are using the findings of Svenaeus and Antonovsky as a background to our approach.

Fredrig Svenaeus is a philosopher of medical ethics whose work has been heavily influenced by the Heidegger's Phenomenological view. While Heidegger was focusing on the subject of a being itself, Svenaeus [4] is focusing more on people's health and the meaning of medicine in people's lives. Svenaeus defines health as a homelike being-in-the-world and describes the patient as a person who has an illness and who seeks help. [4] For gaining better understanding of what means *homelike being-in-the-world*, it is fruitful to look at the other side of the coin; what it is to be ill. The concept of *unhomelike being-in-the-world* is also a concept of Svenaeus[5]:

"Health, in contrast to this frustrating unhomelikeness, is a homelike being-in-the-world in which the lived body in most cases has a transparent quality as the point of access to the world in understanding activities."[5]

Illness is something that alienates one from one's homelike being-in-the-world. It means that one's future and past seems to be alien, while compared to what it was before the illness. Alienating can be seen as alienating from one's body, in the context of phenomenology of medicine. Nevertheless, the alienation from the body is not sufficient for understanding the phenomenology of illness. The alienation from homelike being-in-the-world is a wider conception where illness is seen in a broader way. Illness is a critical change in meaning-structure within the self (the person) and the self is not identical with the body of a person. It is also possible for one to gain homelikeness back without the disease (that is biomedical) being cured and thus illness is something that is temporally alienating from homelike being-in-the-world.[5] Like Svenaeus was showing, health and illness are very personal by nature and we must always understand the individual experience of those (which differs from person to person). Thus, we must try to find ways to support one's gaining of the health in a sense of homelike being-in-the-world, not only in a medical context.

Antonovsky [6] is highlighting the need for a different concept than *pathogenic* orientation (a view that is focusing on diseases and bio-medical factors) that is dominant in the current medical research and healthcare. *Salutogenetic* model that contains the concepts *Sense of Coherence (SoC)* and *General Resistance Resources (GRSs)* is a model in which the focus is on supporting health and well-being by focusing on salutary aspects and seeing the entire person rather than just the disease or illness. Antonovsky sees that health is a continuum where in the other end is health and in the other is illness. Each of us is in some place along that continuum in some specific time. [6] There is a similarity with Svenaeus' *homelike being-in-the-world* [4] that also was time dependent; it is altered by time. The main point in both Svenaeus' and Antonovsky's works seems to be that people are persons and they cannot be treated as mere medical objects. Moreover, people must be supported in such a way that they can have meaningful goals and ways to achieve those goals. In the Copilot, this kind of approach is put in operation and chapters four and five are dealing with this issue.

Thus, people experience their health or illness in different ways and in different situations people have different needs and desires [7]. Like Svenaeus is pointing out, there is very much variation in people's experiences of health. Hence, it is obvious that the people themselves are the best experts of their life, because they are living it. Even if healthcare professionals or some other people could possess a greater amount of information about the sicknesses and body of a human being, they are not living the life of the people having those diseases. Healthcare professionals should be

servicing the needs of the patients rather than only giving them paternalistic solutions from the perspective of a professional. Patients should have the experience and the feeling that there is “Nothing about me, without me” [8].

3 Work Informatics as a Research Framework for the Coper-pilot

The Coper-pilot (2011-2014) is a sub-project of a bigger EU-funded Pump-project that aims at developing well-being services to citizens. The pilot is carried out by a research team from University of Turku and co-supported by City of Turku, CGI Inc. and Turku Science Park Inc.

In the Coper-pilot, the focus is on patients with a cardiovascular disease living in the Turku municipality area, Western Finland. The purpose of the Coper-pilot is firstly to clarify the vision created in the Pump-project, a vision of a citizen that takes on a more active role in their health and well-being. Secondly, the pilot aims to deliver citizen-oriented e-health services that actually meet the needs of patients with a cardiovascular disease. The main goal is to define requirements of the patients from human-scale information system perspective. In order to reach these goals, principles from Work Informatics are applied.

Work Informatics is a multi-disciplinary research area (at University of Turku, Turku School of Economics, Information System Science) that seeks to solve problems in information systems development by approaching issues from a social perspective. Thus, the focus in Work Informatics is on different dimensions of work, such as individual and collaboration work. Furthermore, the phenomenon related to work cannot be studied in a laboratory environment, because work is a social construct and thus, a more social approach must be utilized.

The main thesis of Work Informatics is the concept of inseparability of work and information systems. By this we mean that data processing activities cannot be isolated from other activities, not even for the purpose of designing information systems. This derives from the concept known as the inseparability postulate that states that an information system cannot be altered without altering the organization it is related to. Likewise, the organization cannot be altered without altering the information system. [9]

In Work Informatics, information systems and their activities are seen to be unconditionally rooted in the activities of human beings. That is, the computer is not seen as an artifact that has a meaning in itself. In other words, a computer cannot do anything on its own because there is always human activity behind an action. This being said, the computer is only a tool of human activity. [10] With this principle in mind, we now have excellent guidelines for solving problems in real world such as those in the Coper-pilot.

The theoretical foundation of the Coper-pilot is taken from Work Informatics. As stated before, focus in Work Informatics is on work processes. Since the focus group in the Coper-pilot is a group of patients with a cardiovascular disease, the concept of work needs to be revisited. Merriam-Webster Encyclopedia defines work as “an activity in which one exerts strength of faculties to do or perform something”. While this is a working definition, it however does not completely apply in our case. For a

better understanding of the concept, we interpret work as a *goal oriented action*. Let's take a patient with a cardiovascular disease performing daily tasks related to their condition as an example. Here the action of performing the task to maintain the condition is driven by the prospect of a better health. By applying principles from the Work Informatics framework we seek to get an understanding of the phenomenon taking place in the patient's context.

4 Fracture and Goal-Oriented Action

Patient participation is very important in health care. Without patient commitment and adherence to treatment the desired treatment outcomes are very hard to achieve. In order for us to understand patient commitment and adherence to treatment, we have to consider the issue from the patient's point of view. This way we get insight into a particular patient's characteristics and needs affecting health related issues and motivation to treatment. By understanding the patient's point of view, we may be able to affect his commitment and adherence to treatment.

The self-determination theory is one theory that considers behavior change and motivation of a human being. The theory has been used in health care to understand the motivation of patients, for example to treatment adherence. By using the principles of Self-determination theory in health care interventions, the achievement of health advancing goals and the autonomy of the patient may be supported [11-13]. Self-determination theory sees motivation as a continuum from amotivation to extrinsic motivation to intrinsic, self-determined motivation. The theory sees intrinsic, self-determined motivation as the most sustainable type of motivation, as behavior that is interesting and pleasant in itself is intrinsically motivated. Also, intrinsic motivation is the most autonomous form of motivation, as the amount of autonomy grows when moving along the continuum towards intrinsic motivation. But, when thinking about health care and actions that it requires from the patient, it may be recognized that these actions in themselves aren't necessarily interesting or pleasant for the patient. So, instead of seeing motivation solely as intrinsic motivation situation should be seen as these actions can also be enchanted by extrinsic motivation. Therefore, as intrinsic motivation is seen as the most sustainable type of motivation, one should attempt to reach a type of extrinsic motivation that resembles intrinsic motivation the most. [14] For example, in the Coper-pilot project we are looking reality from the perspective of the citizen [2]. Citizens in this context are seen as wider than the mere object of healthcare; they have their own lives outside of role of the patient. Citizens have rights and duties and thus citizen must be treated as the active actor of their own lives and wellbeing. If people are merely treated as objects of healthcare how they can be expected to take care of their health and wellbeing. This reality is in its optimal state when the citizen is feeling "homelike", as presented in chapter two of this paper. But sometimes this reality may be fractured. This fracturing can be caused by a big, surprising and especially unpleasant change in the state of the citizen, the surrounding interaction partners, or the surrounding environment. If this change is coupled with a profound acknowledgement of its existence, a *fracture* is created. A fracture causes contradictions between the present state-of-being and the objective state that is based on one's own values. These

contradictions and the unpleasant feeling caused by the fracture may lead to a *goal-oriented action*.

A goal-oriented action is purposeful and determined functioning leading towards one's own personal goals and objectives. The purpose of this action is to fix one's state-of-being caused by the fracture, and to restore the optimal state of feeling homelike. A goal-oriented action is characterized with persistent efforts to overcome the contradictions and barriers between one's present state-of-being and the desired objective state-of-being. This necessitates that one experiences the fracture as such a significant change that one wants to fix this unpleasant state-of-being caused by it. In addition to this, a goal-oriented action may occur only if the citizen believes that reaching the desired objective state is overall possible. The citizen must also trust in his own capabilities in achieving the desired objective state. When thinking about goal-oriented action as described above, we can easily see that performing and engaging in goal-oriented action requires motivation from the patient's behalf. But as the fracture in itself isn't that interesting or at least not that pleasant, the motivation is hardly only intrinsic. Instead, the motivation of a goal-oriented action can also be extrinsic.

As stated before, one should attempt to also reach a type of extrinsic motivation that resembles intrinsic motivation the most when trying to achieve the most sustainable form of motivation possible in actions that can't be only excepted to be intrinsically motivated. Self-determination theory recognizes that the development of motivation and one's own personality are based on human being's innate tendencies to psychological growth and to the integration of the self. The theory recognizes three psychological factors that enable these innate tendencies, and the development of motivation: competence, autonomy and relatedness. [14-16] These three factors are recognized as human being's basic needs, and supporting these needs is pivotal for motivation [15]. Competence implies that one needs to believe in his own capabilities to affect outcomes in order to be motivated. [14, 17] Also, one needs to have autonomy instead of feeling compelled by someone else to act in a certain way [14]. When having autonomy, one feels that he himself is making the decisions regarding one's actions [17]. Relatedness refers to one's social environment and connections to other people. According to the theory, one has a natural tendency to feel connected to, to be supported by and to be understood by other people. [16, 17]

So, in order to be able to develop the extrinsic motivation to the most sustainable form possible, the three factors affecting motivation – competence, autonomy, and relatedness – have to be supported. Especially the support of autonomy is seen very important when considering motivation for health related activities, since it has been recognized that autonomous motivation has resulted in better treatment commitment and adherence. These in turn result in better treatment outcomes. [14] Kosciulek and Mertz [18] have shown that people's power over their own rehabilitation has a positive relationship with empowerment and further, there exist a positive relationship between empowerment and quality of life.

There are several ways to support patient autonomy. First of all, the patient's point of view of his own health conditions, the disease and its treatment should be recognized, considered and understood. [19-21] Secondly, the patient should be offered several different types of treatment possibilities, from which the patient may select the one that suits him the best [18-24]. The patient should also be encouraged to

use his own initiative by encouraging him to take part in the decision making regarding issues affecting his health [20-22]. Because people are the experts of their needs and how these needs are best met, they should also have opportunity to exercise control over their daily lives [18, 23-24]. To enable this, the patient should be given information about the disease, treatment and the effects of his own actions [19-22] and moreover there should also be appropriate long-term support available [18, 23-24]. In addition to these, the patient shouldn't be pressured to act in a certain way. Instead, by supporting the patient's autonomy, he should be allowed to make the final decision as how to act.

When considering motivation from the point of view of Self-determination theory, it is quite clear that the patient's needs related to health care and the homelike-being are taken into consideration. By supporting patient's feelings of competence, autonomy and relatedness, the patient's own point of view to his health conditions and his motivation to take necessary actions to improve his health are recognized. Using the principles of Self-determination theory could therefore be quite valuable when developing healthcare interventions that truly want to consider the patient and his feelings and also answer to the patient's individual needs.

5 E-health for the Citizens

5.1 Coper pilot

In the Coper-pilot, the development of the e-health services is based on the citizen's point of view. The pilot seeks to reply to the on-going national agenda in Finland that emphasizes the importance of self-care as well as the utilization of IT in providing health services, and the present problems in the efficiency of public health care. The purpose is to find out whether e-health services could help in solving the existing problems and needs. We are focusing on how to get and enable patients to take on a more active role in their own health care, and what are the mechanisms behind the motivation to do that. The aforementioned concepts of fracture and goal-oriented action are used as the basis of our approach in the Coper-pilot.

5.2 Pre-evaluation study

In 2012 a pre-evaluation study was initiated. The study was conducted as part of the Coper-pilot and the aim was to investigate the needs of patients with a cardiovascular disease towards e-health services. In the study it was discovered that the patients have multi-factorial needs for e-health services [25].

5.2.1 Participants and data collection

All participants were recruited outside the hospital. The target group consisted of seven participants. Individuals were selected in random manners. Ages ranged from 60 to 88 years. The type of the cardiovascular disease was not of high importance, since the purpose was to study cardiac patients as one group in whole. Eligible

participants were approached personally and both written and verbal consent obtained from those who agreed to participate in the study. [25]

Data was collected using thematic interview method and themes were derived from the research question. These themes were: needs and preferences, prior experiences with e-health services, benefits in daily life, use of e-services, challenges and motivation. Participants were interviewed once and all interviews took place at their home except for one which took place at University facility. Interviews lasted from 45 to 100 minutes. Interviews were auto taped with participants consent and afterwards transcribed. Transcribed data accumulated up to 74 pages. [25]

5.2.2 Main results

The most important needs were categorized as follows: need for information, communication, social support and self-care. Need for information was one of the most important themes discovered. This theme was further broken into advisory, counseling and access to reliable information. Participants wanted information about different states of pain, medication, symptoms, daily life and information related to recovery. In addition, participants hoped for an easy access to information. [25,26] Forster et al. [27] discovered that information provision improves patient's knowledge of their condition and can increase patient satisfaction. They also found that information provision has an effect of reducing patient depression. They, however, add that information provision should be continual, since it has more effect then. Health portals offer tools to fight the gap in information provision by enabling access to different information [28].

The second need discovered was the need for communication. The participants had experienced difficulties related to communication with healthcare professionals. Many experienced that they were not given a chance to participate in their care. They felt that they were underdogs and outsiders in their treatment. [25,26] While paternalistic behavior can be benevolent and well intentioned, it does have an effect of creating and maintaining an unhealthy dependency towards health care professionals [29]. The need for a trusting relationship between doctor and patient and the need for trust in the medical system as well, seems to be of critical importance for the patients, in order to communicate electronically with their doctor. In addition, communication via computers also affects the level of trust that the patients experience in their doctor and their willingness to sustain their relationship. The informality and the personal language used in the e-mediated communication are examples of such elements that can stimulate the trust in patient-doctor relationships. When a trusting relationship exists, e-mediated communication offers the patients an opportunity to contact the doctor when and where it suits best for each personal life circumstances. The patients value this kind of communication because it is a relief that they can tell prevailing worries to their doctor. The use of e-mediated communication can also enable them to ask such questions that they would not otherwise brought up. [30]

Social support was also an important theme, though perceptions about it varied. For some, support from family was the most important. For others, support from the

outside or personal support was better. Participants, however, all agreed that support is important. It does not matter whether it comes from the family or from outside.[25] Based on this, eHealth services could be a source of social support for the citizen. For example, studies focusing on patients with breast cancer, arthritis and fibromyalgia suggest that participating in online support groups can create a feeling of emotional support. It appears that participation in online support groups can generate empowering processes and outcomes related to social and emotional support, such as increased social contacts, enhanced social well-being, avoided social isolation, finding recognition and understanding and feeling less lonely in coping with the disease. [31-32]

Self-care involves regular maintenance tasks such as managing multiple medications, engaging in physical activity and healthy diet follow-up [33]. Participants showed interest towards time management, document management, medication management, monitoring and health management. Time management was important to many. This included calendar and reminder features through which one could follow and plan tasks. [25] Successful rehabilitation means changes in relationships between an individual and his environment. Those changes are results of goal-directed action, and amongst other things, it manifests itself by simplifying daily life. [34]. When a citizen is trying to make a difference to their health-related behavior, health care professionals can assist their effort effectively via new technologies [35-36]. For instance medication management, self-management skills, and patient experience with care can be positively affect by the use of health IT applications [37]. Automatic reminders and personal messages, which take one's prevailing life contexts into account, are examples of such health communication solutions. A citizen, who receives tailored lifestyle information about nutrition behavior or physical activity, is more likely to meet the guidelines than a citizen who receives only generic information [38].

5.3 Current study/Situation

At the moment Coper-pilot study is in progress and it is in data collection phase. We have selected citizens with some cardiovascular disease as the target group of the pilot. For a patient with a cardiovascular disease, the fracture is quite obvious: the disease itself. Our purpose is to find out the mechanisms needed for the citizen having a cardiovascular disease to be empowered and motivated to commit, participate and adhere to the needed treatment, that is, how to get the citizen to engage in goal-oriented actions that would fix the fracture. In addition, our aim is to find out the mechanisms to help the citizen live his own everyday life that includes the cardiovascular disease in the best manner possible, and how to get the citizen to the homelike state-of-being described in chapter two. We believe that e-health services could provide solutions that help the citizen live his own everyday life with the disease as well as, when correctly developed, could enable and motivate him to take a more active role in his own health care.

6 Conclusions

It is obvious that if we want to change the problem of half of the patients not following treatment guidelines we must change something in healthcare. One solution, that seems to be promising, is to give more focus on people's experience of their health and well-being. We must understand that no given orders from doctors or other healthcare professionals are effective if people do not follow them. By respecting peoples' autonomy we can find ways to motivate them so that they will themselves be the core actors of their own well-being and health. However, there must be tools (in this case, e-health solutions) for people to take that control, and information technology can be one of those tools. The tools must be designed and implemented in such a way that those tools fulfill the needs of citizens, not only the needs of the healthcare system, or we will face the prominent problem of non-commitment of citizens. In the Coper-pilot this citizen-centric approach is taken as a core value for achieving better e-health solutions.

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