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Enhancing co-responsibility for patient engagement.

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Abstract: In this paper we share a theoretical perspective of co-responsibility, developed by a consortium of a university, a private company and a hospital. On this perspective we will base design interventions towards improving the experience and specifically the engagement of cardiovascular patients after the disease has occurred, a phase referred to as secondary prevention. Co-responsibility argues that responsibilities of different people in society are intertwined with each other, not in the sense that people share the same responsibilities, but in the sense that people's responsibilities are interdependent. We discuss the opportunities and challenges for design from a co-responsibility perspective through examples of co-responsibility encouraging design artefacts. We argue that such an approach offers the opportunity to support more sustainable engagement by attuning patients, their family and friends, and medical professionals to each other to increase their team performance, address their internal motivation and create a win-win situation.

Keywords: co-responsibility, interdependence, patient engagement, cardiovascular, secondary prevention

1. Introduction

This position paper describes the foundations of a collaborative research between Eindhoven University of Technology, Philips and the Catharina hospital, all located in Eindhoven, the Netherlands. The focus of this research is on secondary prevention for people diagnosed with a cardiovascular disease (CVD), one of the main causes of death in the Netherlands (Dis, I van Buddeke, J Vaartjes, I. Visseren, F.L.J. Bots, 2015). Secondary prevention means that the disease, in this case CVD, has already occurred (so-called ‘patients’) and in this period a healthy lifestyle can reduce readmissions (Annema, Luttik, & Jaarsma, 2009), reduce complications (Billinger et al., 2014) and influence their quality of life in a positive way (Savolainen, Kautiainen, Miettola, Niskanen, & Mäntysetälä, 2014). Examples of lifestyle related risk factors in both primary and secondary prevention are hypertension, overweight, smoking, high cholesterol, stress and physical inactivity. These risk factors are mainly related to coronary artery diseases (CAD), which is a main cause of CVD.
mortality (Dis, I van Buddeke, J Vaartjes, I. Visseren, F.L.J. Bots, 2015). In order to help a patient with CAD, medical professionals can perform several interventions, such as prescribing medication, performing a cardiac catheterization and/or applying one or more bypasses. However, the risk of narrowing of the coronary arteries remains and will only increase with age (Hartstichting, 2016). Therefore, it is important that, next to this medical intervention, a patient adheres with the lifestyle related advice in the established treatment plan; not only in the period around the intervention (short-term), but also in the period long after the intervention (long-term), when contact with the healthcare providers has become less intensive.

The World Health Organization has defined adherence as “the extent to which a person’s behavior – taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a healthcare provider” (WHO, 2003, p.3), and despite the generally known benefits of a healthy lifestyle and the alarming condition of a patient, patient adherence is low (WHO, 2003). This non-adherence is a complex problem, as it is influenced by several factors, which are divided by the WHO in social and economic factors, therapy-related factors, condition-related factors, healthcare team and system-related factors, and patient-related factors. Furthermore, adherence is part of the patient engagement process, which includes many other patient behaviors that are required in order to make optimal use of the healthcare system (Center for Advancing Health, 2010; Gruman et al., 2010), such as understanding the disease, evaluating treatment options, negotiating the treatment plan, monitoring and managing symptoms and sharing medical data. All these engaging behaviours influence the eventual adherence to the treatment plan.

In our collaborative research we aim at increasing patient engagement through design. We believe that responsibility is a critical element to consider in this context, as it is often a point of discussion around adverse health outcomes, and a dynamic concept that changes over time and in between people. Currently, there are several evolving trends in healthcare that cause responsibilities to shift.

First, borders between hospital and home are fading, as well as the borders between primary and secondary care. One of the factors contributing to this is a change in how hospitals are remunerated by insurance companies. Instead of basing payment only on the amount of interventions taking place, insurance companies increasingly base remuneration on factors indicative of the quality of care. In the US the first changes have already been made (Berenson, Paulus, & Kalman, 2012); in the Netherlands the first trials are now running (Veghel, 2015). The factors considered are not linked only to the hospital. Some factors that are used to measure this quality of care are measured in a patient’s home environment, such as quality of life, readmission rates, complication rates and mortality rates. As a result, the hospital’s responsibilities in the home environment increase since the patient’s condition in the home environment is becoming directly related to the earnings of the hospital. Next to this, different care organizations from primary and secondary care are working more and more together, merging their responsibilities into one another. Multi-disciplinary teams discuss a patient’s condition and treatment options, sharing the patient’s medical data. These merging responsibilities are being supported by today’s technology. For care organisations to be in touch with each other and their patients from a distance, they can make use of EHealth systems: systems that provide care to patients, using the Internet as a medium.

Secondly, today’s technology also enables patients themselves to be more responsible for their own health by enabling them to keep track of their own vital signs (Stut et al., 2014; Inglis et al., 2010; Orlowski et al., 2013). Patients can use this data to increase their awareness of their own medical condition, and are thus enabled to take action themselves when they believe that is necessary.
Thirdly, empowerment has become a popular term to describe this movement of patients being more involved in care and being enabled to take care in their own hands (Castro, Van Regenmortel, Vanhaecht, Sermeus, & Van Hecke, 2016). However, empowerment indicates that the individual is fully responsible for his or her behaviour, “as it enhances people’s capacity to live their own lives in an autonomous way” (Devisch, 2012, p.146, 147). We argue that the patient is not the only person responsible for his/her health-related behaviour. In section 2 we explain why we think so, by means of highlighting parts of the current, relevant discussion on individual versus social responsibility. We will then introduce the notion of co-responsibility, and in section 3 we will explain why taking co-responsibility as a starting point for design is an opportunity in the domain of secondary prevention for people diagnosed with CVD.

2. Design Perspective on responsibilities

2.1 Individual vs. social responsibility

People tend to identify a person/party responsible for their adverse health outcomes. As a result, there is a debate on individual versus social responsibility, which is still open (Devisch, 2012). Proponents of individual responsibility argue that people who have caused their own adverse health outcomes should either receive lower priority for care than people who do behave responsible, or share a bigger part of the costs. Opponents argue that this behaviour is a result of the way our society is organized (Harris, 1995). To point out that any serious list of irresponsible behaviour would include a high proportion of the population, Harris listed some of the irresponsible behaviours that could be included:

“Those who indulge in risky sports and pastimes (squash, football, rugby, pot-holing, climbing, hang gliding), those who don’t indulge in sports and thus become unfit or obese, those who have less than an optimal diet (whether in the form of cream cakes, animal fats, hydrogenated fats, animal protein, etc.), or those who eat too much or too little would all have to be included. Then there are those who wilfully or recklessly engage in risky or unhealthy types of employment or frequent dangerous or unhealthy workplaces (fire officers, police officers, the armed services, factory workers, and health care workers). Next we must consider those who wilfully and perversely choose to be dwellers in industrial cities with their inherent risk of pollution, road accidents, and violent crime. We know of course that certain geographical locations are also inherently unsafe. This might be from such features as proximity to nuclear installations or naturally occurring radon, or because country dwellers are so often dangerously distant from a major hospital. It might be because people who live in the north of the United Kingdom or the south of Italy have significantly greater or lesser mortality and know or should know the dangers or benefits of such locations.” (Harris, 1995, p.151)

Anderson (as cited in Buyx, 2008) argues that some unhealthy behaviour is socially very well accepted or even desired (e.g. pregnancy).

This shows that responsibility is more complex than naively thought, and that it is very difficult to assess people on the amount of irresponsible behaviour they perform. To avoid the dualistic thinking (individual vs. social responsibility) in today’s healthcare and to understand how people, next to ‘being responsible for their own agency’ are also always influenced in their decisions by others, Devisch proposes the concept co-responsibility (Devisch, 2012). This way of thinking is also supported by the WHO, who admits that, as explained in the introduction section, adherence is influenced by many other factors beside patient-related factors (WHO, 2003).
2.2 Co-responsibility

“Co-responsibility means that responsibility is never mine or the other’s, but the intermingling of the other’s and me, not in the way that they are shared, but that they intrude or contaminate one another” (Devisch, 2012, p. 146). This concept emphasizes that responsibility is dynamic and in between people. Co-responsibility differs from shared responsibility, as people do not own the same responsibility, but instead have different, individual, responsibilities which are interdependent. In order to make the concept co-responsibility graspable, we will explain it using an example that is generally familiar: team sports, and in particular soccer.

In a soccer match (figure 1), there are two teams, that each have several players in the field. Each player has his/her own role and is responsible for his or her own agency, while also being influenced by the behaviour of all the other players in the field. Next to the players in the field, there are also people at the side-line who influence the game, as a team coach, reserve players or supporters. Furthermore, the team is affected by values, norms, history and strategy of the club they are part of, and the game needs to be played according to certain rules which are taken care of by a referee. Many people and institutions are in this case co-responsible for the course of the game.

Translating this to our context of secondary prevention for people diagnosed with CVD, our main team members are the patients, her or his family and closest friends, and the involved care professionals. Every team member has their own role in managing the patient’s health (consciously or unconsciously) and is therefore responsible for one’s own agency, while also being co-responsible for each other’s behaviour. Medical care is also bound by rules, set by the hospital, insurance companies and the government, who again also influence each other. As in a soccer game: the more steps that go well in the process of the team, the higher the probability of success is. In a well-performing soccer team, the players are attuned to each other, which means that when one makes a mistake (e.g. loosing possession of the ball), or when the counterparty prevails in a different way, the whole team will work together to reduce the impact of this. In both cases, the team has one shared
goal, of which the different team members can extract different values. ‘Reaching an optimal health condition’ contains different values for a patient, then it does for a medical professional who supports the patient in this process.

Lauermann and Karabenick (as cited in Fishman, 2014) distinct ‘feeling responsible’ (internally accepted responsibility) from ‘being held responsible’ (externally imposed responsibility). Bacon (as cited in Fishman, 2014) pointed out that feeling responsible is related to internal motivation and self-regulation, while people who are being held responsible, are more likely to only apply effort as long as there is external control. Translating this to the patient-doctor relationship this means that it is likely that a patient who is ‘following doctor’s orders’ (compliance) stops applying this effort as soon as the contact intensity between them drops. In their self-determination theory, Ryan and Deci (2000) suggest that the more internalized, or autonomous/ self-determined, a motivation is, the more similarities it has with intrinsic motivation. And in turn, more autonomous motivation is associated with more engagement in education (Connell & Wellborn, as cited in Ryan & Deci, 2000), and with greater adherence in health care (Williams, Rodin, Ryan, Grolnick & Deci as cited in Ryan & Deci, 2000). (Autonomous in this case referring “not to being independent, detached, or selfish but rather to the feeling of volition that can accompany any act, whether dependent or independent, collectivist or individualist” (Ryan & Deci, 2000, p.74.).) To stimulate sustainable (long-term) patient adherence, it is therefore important to (re)shape (co-)responsibilities between patients and their medical professionals, in order to address their internally accepted responsibility and support autonomous motivation.

2.3 Different layers of co-responsibility

Devisch (2012) uses co-responsibility mainly to explain the relationship between an individual (patient) and an institution (f.e. the hospital) or society. It can however, also be used to describe the relationship between individuals within our society, as we have shown in the soccer example. Figure 2 shows the main layers of co-responsibility in a secondary prevention context.

**Figure 2:** Different layers of co-responsibility in the secondary prevention context. Our society (1) affects people’s responsibilities by its norms and values and infrastructure. The hospital (2) is part of this society and mainly influences (3)
the medical professionals working there, but also (4) the patients and (5) their family and friends visiting the hospital. Patients are responsible for their own agency (6), but act within society and therefore their responsibilities are intertwined with societal responsibilities, as are responsibilities of family and friends (7). Next to being responsible for their own agency, patients and their family and friends are co-responsible for each other’s behavior (8), as are patients and medical professionals (9), and family and friends and medical professionals (10). (11) Represents the co-responsibilities of the patient, their family and the medical professionals, affected by the hospital and within our society.

Patients, their family and friends, and medical professionals influence each other on a personal level (8, 9, 10 & 11), positively and negatively, all with their personal knowledge and skills. They are also affected by norms, values, medical rules and infrastructure of the hospital (the medical professionals more then patients and their family and friends) and all are influenced by societal norms, values and infrastructure.

The focus in this research project is mainly on the hatched sections, the co-responsibilities of patients, family and friends, and medical professionals on an individual level, while acknowledging the influence of the hospital and society. We strongly believe that taking co-responsibility as a starting point for design can help to support patient engagement, and so increase treatment adherence. In section 3 we inquire design opportunities and challenges by means of analysing two examples of concepts that embody co-responsibility. These examples do not address co-responsibility in a healthcare setting, but are examples taken from other application domains, of how physical products may invite co-responsibility.

3. Opportunities and challenges

3.1 Zhòng Zhòng

Figure 3: Zhòng Zhòng, a design by Philémonne Jaasma, Zheliuyi Wang, Samantha Peeters, Jacquelyn van Kampen and Matthijs van Leeuwen (2010) Eindhoven University of Technology, department of Industrial Design.
Concept description

The first example of a concept that embodies co-responsibility is Zhòng Zhòng (figure 3): a toy designed for Chinese children, that aims at teaching them how to share goods and attention with other children. It was designed by students from the department of Industrial Design, Eindhoven University of Technology, for the context of Chinese kindergarten. Because of China’s former one-child policy, many children in cities grew up without siblings and therefore did not learn how to share, in their home environment. The design exists out of several tubes, that each have two sides which both contain RGB LEDs. One of these sides has a predefined colour (red, green or blue) and acts as the ‘sending side’. The other side acts as the ‘receiving side’. When a child connects his sending side of the tube (f.e. coloured red) to the receiving side of the tube of another child (f.e. coloured blue), this receiving side mingles the new ‘received’ colour with the colour that it already had (f.e. into purple). In this way children can ‘share’ their colours with others. Each sending side contains 3 RGB LEDs. For every time a child sends colour to another child, one of these LEDs will turn off, teaching the child that sharing sometimes contains a loss (in this case a bit of light). On the other hand, when sharing light with others, the mingled colour of the receiving side will maintain it’s brightness, while both sides of the tube automatically start losing their brightness when a child does not share for a while. When a child has shared so much that his sending side is out of light, he has the opportunity to recharge this side at a docking station. This is not the case when a child has an empty tube because of not-sharing.

Relevance for co-responsibility

In this concept every child is responsible for his or her ‘own’ tube, and at the same time all children are co-responsible for the coloured light in the tubes of others. Participation has become visible, and ‘loss of light’ is turned in something positive: everybody can see how much you have shared (instead of how much you have lost). Performing co-responsible behaviour in this case gives the opportunity to create a win-win situation: sharing colours means for the receiving child that he can experiment with creating different colours, maybe even try to create his favourite, while for the sending child it means that the tube will keep shining brightly on one side, and shows the amount of participation on the other. This visibility of participation also stimulates children to encourage each other to share: When the receiving side of a child’s tube has no colour, other children can act upon that by sharing their own colour with this child; When the light is fading in both sides, other children can encourage this child to share his own colour with them. This visibility of participation so has the opportunity to support the children in attuning to each other, inviting a spirit of co-responsibility.

Comparing the concept of Zhòng Zhòng to a situation in which the responsibility of sharing is externally imposed by someone else, for example a teacher or a parent telling the children “that they have to share their goods with other children”, one can argue that using Zhòng Zhòng, children are more autonomously motivated to do so. It shapes the way children interact with each other, and shows the opportunity to address their internally accepted responsibility.

The situation for which Zhòng Zhòng was developed differs of course from the secondary prevention context because all participating children have a similar role, while in the secondary prevention context the roles of the involved people can vary greatly.
3.2 Wearable team coach

Figure 4: Wearable team coach, a design by Sander Bogers (2011) Eindhoven University of Technology, department of Industrial Design.

Concept description

A second example of a concept that embodies co-responsibility is Wearable team coach (figure 4), which aims at visualising ball possession of children playing basketball in high school in an unobtrusive way, to support social play. In high school sports teams, the skill level of the different players of a team can vary greatly. This can result in situations in which only a few players are highly engaged in playing the game, while other, less skilled, players get excluded. The concept wearable team coach visualises ball possession percentage on every player’s shirt, using five light stripes that are placed at the side of the body on hip height. The higher one’s ball possession percentage, the more stripes light up.

Relevance for co-responsibility

As in the concept of Zhòng Zhòng, wearable team coach supports the team players in attuning towards each other by making them aware of each other’s participation, inviting them to act co-responsible. As the lighted stripes are, next to being visible for others, also visible for the players themselves, Wearable team coach also has the opportunity to increase self-awareness. In the situation of Wearable team coach, players have the ability to directly increase the participation of others by throwing the ball at them. Wearable team coach is a concept that is designed for the team, instead of the individual, in order to let the team perform better in terms of engagement in the process. In this case that is not per se directly beneficial to reaching the shared goal of winning the game, but in the context of a team of various people with various skill levels, of which the composition also changes for every game (due to random picking and dividing students from a school class), it does help in attuning the team members to each other and increasing the fun and engagement overall.

A challenge of designing for co-responsibility that is pointed out by Wearable team coach is that the design needs to fit the needs of different members in one team, and also the needs of different teams of people. Also in our secondary prevention context there are various people within one patient-doctor-family team, and various patient-doctor-family teams.

Of course the situation for which Wearable team coach was developed, and Zhòng Zhòng as well, differs from the secondary prevention context in the way that nobody is seriously ill, which brings along different emotions. Considering this, another challenge of designing for co-responsibility in the secondary prevention context is on supporting co-responsibility without reminding patients constantly about their illness. Organizing one’s environment to support engagement, and increasing
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Awareness of the self and others as in Wearable team coach, may cause the patient to ‘feel like a patient’, which is generally not desired. There is more to life than being ill, and always being reminded of a disorder will not be beneficial for a person’s quality of life. This is also true for the informal caregiver, who is often a family member and should not be forced to be constantly reminded of the care process.

4. Conclusion and further considerations

We have shown that designing from a co-responsibility perspective is an opportunity in the domain of secondary prevention for people diagnosed with CVD. Effective co-responsibility design can encourage a spirit of co-responsibility, and so has the opportunity to create a win-win situation for all involved parties, taking into account the different values they attach to a shared goal. Design for co-responsibility also has the ability to increase awareness of the self and others, and therefore to support team members of a patient-family/friends-medical professionals team in attuning to each other to increase team performance. By shaping the communication and interaction between patients, their family and friends, and medical professionals it has the ability to address internally accepted responsibility, stimulate more autonomous motivation, and therefore support more sustainable engagement. In the continuation of our research, we will look for a better understanding of co-responsibilities by designing physical products that embody our vision of co-responsibility within the context of secondary prevention for people diagnosed with CVD.

References


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