WeCAIR
Hybrid Intelligence Portal (HIP)

Supporting a healthy dyadic lifestyle following a myocardial infarction using eHealth technology

Master Thesis by Julian Houwen

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Master thesis **Strategic Produc Design & Medisign**

Supporting a healthy dyadic lifestyle following a myocardial infarction using eHealth technology

Experiencing a Myocardial Infarction together.
Partner as co-patient in lifestyle change

Defended on 23-07-2021

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EXECUTIVE SUMMARY

Problem

In the current care pathway for patients suffering from a Myocardial Infarction (MI), a paradox has been identified in long-term chronic care: modification of cardiovascular risk factors reduce mortality and prevent recurrent cardiac events. However, MI survivors rarely change their lifestyle and relapse often in old habits.

The identified cause within the system is a gap created by a lack of professional and social adherence support in relation to cardiovascular risk management. Research has shown how social support from a partner can improve lifestyle change adherence. To fill the gap, this study looks at how the patient's partner can be supported and empowered by the healthcare system to positively fulfill this role. Therefore, this strategic design thesis aims to develop a tangible strategy for the Hart Long Centrum of the LUMC by answering the following research question:

"How can partners of chronically ill patients, that suffered from a MI, provide effective and positive support for the patient to maintain long-term preventive lifestyle changes by means of an eHealth innovation linked to The Box?"

Dyadic Opportunity

The partner of the patient is able to influence the patient's health behaviour and motivation through the dyadic nature of their relationship. Therefore, a new perspective has been identified for 'The Box' to stimulate long-term preventive lifestyle change; using positive dyadic communication and support to influence the illness perception of patients and partners. This offers the opportunity to create a parallel track to bridge the chronic care gap. The track will be next to the current care pathway, in the form of an eHealth intervention that complements the existing 'The Box' innovation.

Dyadic Experience

Each individual in a couple, who have experienced a MI, goes through their own grieving process after a life changing event such as transition from a 'normal life' to a chronic illness. Within this process it has been shown that the needs of the partner and patient change over time. This dyadic adaptation process has been examined and the dynamic key needs of the partner have been identified:

- How can the partner support the right way at the right time?
- How can the partner themselves be supported?
- How to strive for a relationship where the right balance between 'patient' and 'loved one' is achieved during the adaptation process?

Solution Direction

A future solution is envisioned in which the patient's partner is actively given a central role in participating in long-term lifestyle change:

Partners will be empowered and guided by the healthcare system, by means of an eHealth intervention driven by hybrid intelligence and P4 mechanisms (prevention, prediction, personalization, participation), to positively support the patient in the right way at the right moment in changing their lifestyle in the long term.

WeCAIR - Partner Perspective of the Hybrid Intelligence Portal (HIP)

To make the strategy of influencing patient adherence by empowering and guiding the partner tangible, WeCAIR is designed. WeCAIR is part of a Hybrid Intelligence Portal (HIP) which monitors and guards the balance of human dynamic interactions and needs between partner, patient and care professional. WeCAIR is a user-friendly interface developed from the perspective of the patient's partner. As discussed in the chapter before, the interface has three different main features: (1) Personalized Dyadic Route, (2) Behavioural Support and (3) Lifestyle Education. These characteristics are aimed at empowering and guiding the partner to take on a balanced role in relation to their life partner (the patient) in the adjustment process to chronic illness, in order to positively support the patient in the right way at the right moment in changing their lifestyle in the long term.

Conclusion

The proposed strategic Product Service System (PSS) improves the current care pathway by involving, supporting and empowering the partner in the care process, resulting in long-term adherence to lifestyle changes. Ultimately, this leads to secondary prevention for the patient and primary prevention for the patient's partner.

For the LUMC Hart Long Centrum, this means that by implementing the PSS they will be one step closer to their goal of providing the best clinical and innovative care to patients.

ACKNOWLEDGEMENTS

Because the Covid-19 pandemic makes it a special time to graduate, I would like to say a few words of thanks to everyone who supported and helped me during the graduation process.

First of all, I would like to thank my supervisors; my chair and mentor.

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- Julian Houwen -

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THE PARTNER BOX

Thesis Introduction

Background

In Europe, Cardiovascular Disease (CVD) is the leading cause of death, simultaneously contributing to the growing costs of healthcare (Graham et al., 2007). Moreover, research shows the main cause of the chronic nature of this illness is lifestyle-related.

This risk exposure can be reduced for patients susceptible to the disease by modifying the risk factors using for example lifestyle modification programmes (Janssen, Gucht, Dusseldorp, & Maes, 2012). Therefore, after a CVD event, like a myocardial infarction (MI), patients have to change their behaviour. eHealth technology has the potential to provide support for behaviour change and healthy living, when adjusted to the needs of patients (Breeman et al., 2021).

Currently, the LUMC and National eHealth Living Lab (NeLL) have already developed several successful 'Box projects', containing a number of SMART wearables, which help to provide preventive care directly to the CVD patient at risk. But they are now running up against the fact that if the patient's family context, especially the partner, does not participate and provide the necessary support, the long term therapy adherence decreases (Dalteg, Benzein, Fridlund, & Malm, 2011; Janssen, Gucht, Dusseldorp, & Maes, 2012; Vedanthan et al., 2016).

Research indicates that social support has a fundamental role in health promotion and disease prevention (Doherty, 2004; Vedanthan et al., 2016; Breeman et al., 2021). Interventions developed for partners of patients are more beneficial regarding adherence of the therapy (Janssen, Gucht, Dusseldorp, & Maes, 2012). However, little or no research has been done into the needs of the partner in relation with the MI patient and long term lifestyle changes.

Using eHealth interventions to encourage the partner - instead of just the patient - to adjust their lifestyle is a promising strategy. But in order to develop a suitable and effective eHealth intervention, it is important to identify the partner's perspectives, behaviour and preferences (Breeman et al., 2021).

Throughout this design project, a research will be performed to investigate and explore both conscious and unconscious behaviour and needs, as well as patient-partner interactions and interdependence. Subsequently, the current and future eHealth technologies will be explored to identify a novel solution space. Ultimately, this study aims on creating an eHealth box intervention that will encourage partners of MI patients to participate in a collective life(style) change using SMART technology.

Stakeholders

The parties involved in the research are the TU Delft, LUMC Hart Long Centrum and National eHealth Living Lab (NeLL). This network of stakeholders provides guidance through this master thesis to ensure that a relevant and optimal result is achieved for the benefit of the diverse parties. The main objective is an instructive graduation project and the vision to make a sustainable impact on the healthcare system through meaningful innovation.

TU Delft

This graduation project is carried out as the final part of the curriculum for the master Strategic Product Design at the faculty of Industrial Design Engineering at TU Delft. At TU Delft, as the oldest and largest university of technology in the Netherlands, excellence in education and research is key. One of the major research focus areas for this research is healthcare. The objective of this research field is to bring together technology, medicine and the social sphere. *"Healthcare must become more efficient and effective, and this is where technology from Delft can make a big difference. We are working closely with medical centres and are seeing unimaginable innovation arise at the intersection between the two sciences."*- Tim van der Hagen, Rector Magnificus TU Delft (2021).

TU Delft

LUMC Hart Long Centrum

The goal of the Hart Long Centrum Leiden is to provide the best clinical, referral and innovative care to patients with congenital and acquired cardiovascular diseases and various benign and malignant lung diseases. They aim to provide the best possible care that does not end as soon as the patient leaves the hospital. Therefore, they offer additional care in the form of home measuring equipment and have made it more convenient to keep in touch with the care professional. The initiative is known as The Box. It gives patients the opportunity to take medical data measurements at home via a smartphone or tablet using various devices. In addition, it enables making follow-up appointment with a nurse specialist or cardiologist from the comfort of one's home using a digital consultation system.

LUMC Leids Universitair Medisch Centrum

NeLL Network

NeLL facilitates both long and short-term scientific research in eHealth, is at the forefront of the development of validation methods of eHealth innovations and plays a pioneering role in the creation of internationally applicable eHealth standards. NeLL aims to co-develop the sustainable care of the future: the right care for the patient in the right place at the right price. They do this by working together with their network of diverse consumers, professionals, students, scientists and policy makers (both in- and outside the healthcare environment).

NeLL

Problem Statement

Scope

As just introduced, an opportunity to improve the care for Myocardial Infarction (MI) patients has been identified by the LUMC Hart Long Centrum through The Box initiative: *"the patient's partner could be involved in the care and lifestyle change of the patient to have a positive effect on their quality of life"*. However, hardly any concrete research has been done on how the partner of the patient can be actively involved through the care system and what the actual needs are of these partners. Therefore, this design project investigates what lifestyle change exactly means for the patient and partner, why there is a need to involve the partner, how the partner can be included, and how they can exert a positive effect on the patient's health.

Solution space

In this thesis, a product service system (PSS) will serve as a tangible illustration of a developed strategy that will provide a solution to the problem. There are a number of requirements for the framework of the solution direction. The most important requirements are: it should build on the 'eHealth technology foundation' of the already existing The Box innovation, involve the key stakeholders (care professionals, patients and partners of patients) and the solution should preferably be able to be implemented within six months to one year.

Research question

The following question is at the centre of the study:

"How can partners of chronically ill patients, that suffered from a MI, provide effective and positive support for the patient to maintain long-term preventive lifestyle changes by means of an eHealth innovation linked to The Box?"

The 5 PSS Objectives

In this study, the research question will be sought to be answered by means of a Product Service System (PSS) for the client: Hart Long Centrum Leiden. Their goal is to provide the best innovative care. To develop a PSS that meets this goal, the quadruple aim model of Bodenheimer and Sinsky (2014) is used to give a direction for meaningfull and sustainable innovation within the healthcare system. For this purpose, the following 4 pillars are taken into account throughout the process:

- **Patient Experience:** *Does it enhance the patient experience?*
- **Population Health:** *Does it improve population health?*
- **Reducing Costs:** *Does it reduce costs of care?*
- **Wellbeing Care Professional:** *Does it improve the wellbeing of health care professionals?*

Within this study a novel component has been added to the quadruple aim, the **Social Context**. This is important within the new holistic view of care, due to its role and impact on the patient's health management. That is why the following model has been developed: the Quintuple Aim.

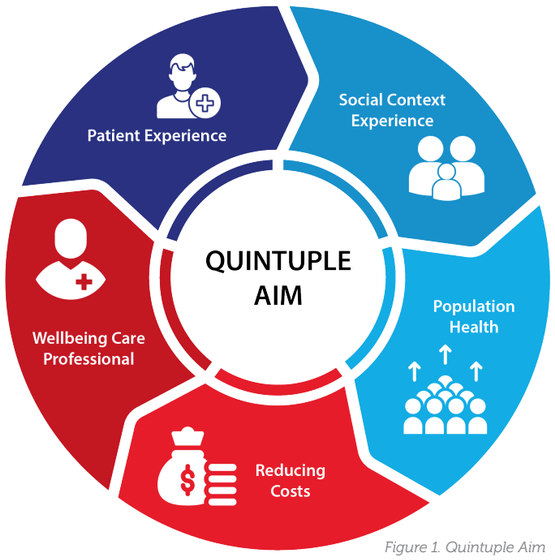


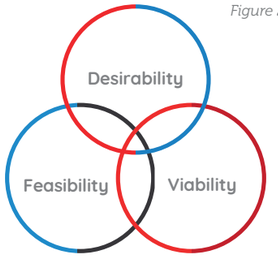
Figure 1. Quintuple Aim

At the conclusion of this study, the Quintuple Aim is used as an objective for the PSS and an evaluation tool to assess whether the proposed PSS has a positive effect on the holistic Myocardial Infarction care system.
The four pillar questions stated above will be discussed and to include all key stakeholders, a final question is added: *Does it improve the experience of the social context.*

Strategic Design Approach

This project was performed from a strategic medisigner's point of view, using a design thinking methodology. The 'strategic design perspective' redefines how the complex problems are approached, identifies opportunities for action and delivers more resilient, fruitful and novel guidelines for a solution.
Central to the research is the double diamond model, which is a simplified representation of the method used (Design Council, 2005). This model represents the process of divergence and convergence that is also reflected in this report. Whilst going through this process, knowledge is constantly being developed and synthesised iteratively and pragmatically (Kleinsmann, 2021). The outcome is constantly tested against the human centred design framework given below:

Figure 2. Human Centred Design



Desirability: Does it address the values and needs for the stakeholders?
Feasibility: Is it technically possible within the foreseeable future?
Viability: Is it likely to become part of a sustainable value model for the LUMC?

The interpretation of the double diamond model is adapted to the most suitable process for answering the previous mentioned research question. The following steps in the design process are performed and form the main sections of this report. See a visualised overview of the process on the next page.

1. Understand
A research is performed to understand the research question that has been formulated. This involves an study via desktop and expert interviews into the elements of the research question, the broader context surrounding the identified possibility (people, organisation and technology), the underlying problems and opportunities for a solution.

2. Empathise
The user and the context, are analysed in qualitative. This means studying the partner of the patient, their behaviours and how they interact within the context to understand their (latent) needs using an empathic approach.

3. Imagine
In the imagine step, creativity and innovation are used to expand the solution space in order to find fruitful and novel solutions to problems. This includes reframing the problem towards other fields and looking to future possibilities. The insights gathered from this, are used to determine a solution direction.

4. Design
The design phase is characterised by the development of a tangible strategy in the form of a Product Service System (PSS). The aim is to set the first step in the strategy towards the future solution with a concrete tangible concept.

5. Deepen
During the deepening phase, the interaction with the PSS and the stakeholders is elaborated in all its subtlety. This provides more in-depth insights into the interaction with users, and results in opportunities to refine and implement the PSS.

6. Evaluate
The evaluation phase will assess whether the objectives of the Quintuple Aim have been achieved. This will determine whether the designed PSS will achieve the intended meaningful and sustainable result of improving the client's care system.

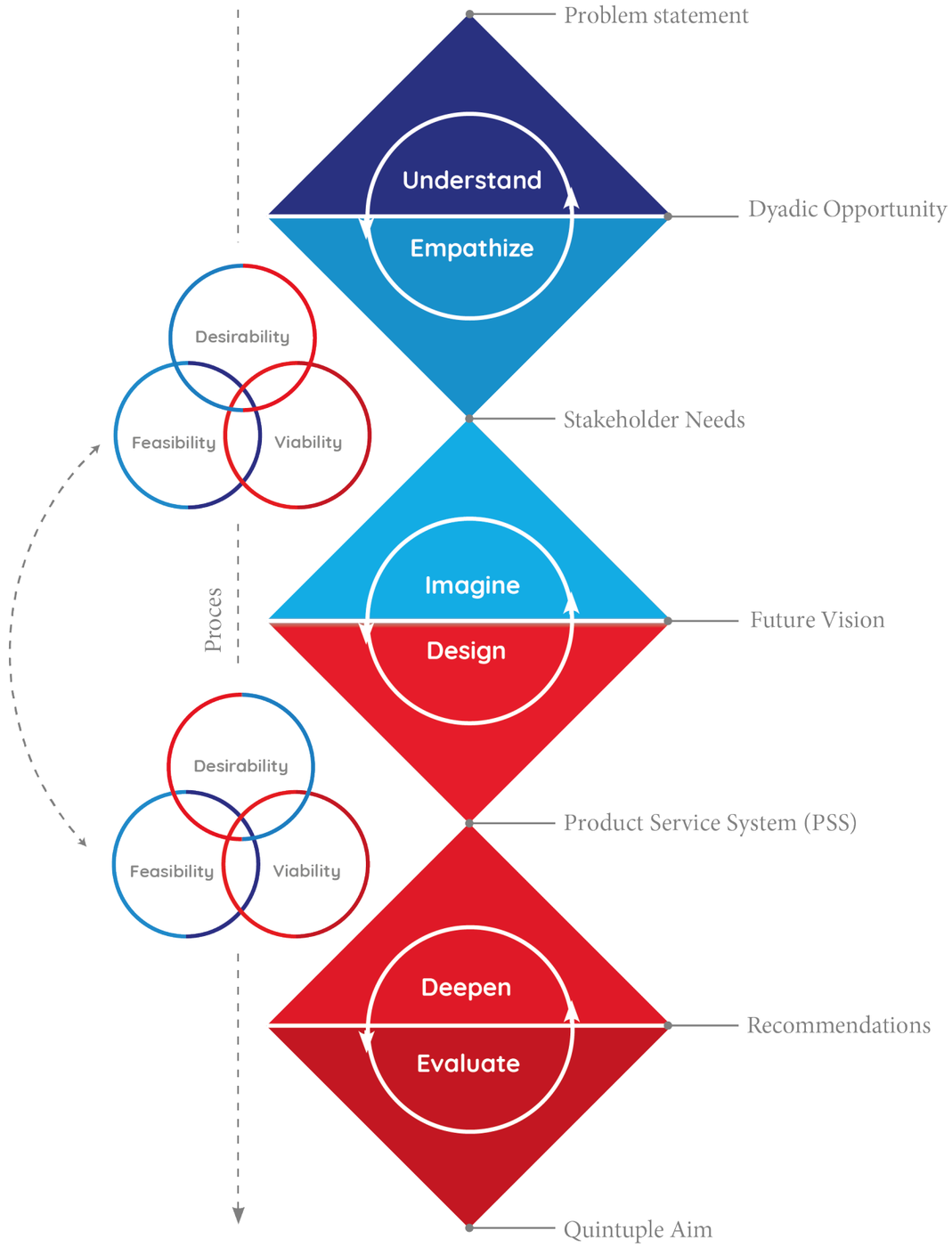


Figure 3. Design Process

1. UNDERSTAND

The aim of this chapter is to gain a better understanding of the established opportunity of involving the patient's partner in lifestyle changes for prevention using a Product Service System. First, the growing need for prevention and the associated shift in the health system is studied. Based aidentified. Finally, a solution direction is described to address the paradox.

1.1 The Problem

Macro Problem

People increasingly survive a cardiovascular events, due to improved acute care. Patients have a higher chance to live on after their heart disease is diagnosed. The downside of this is that the number of people with a chronic heart- or vascular disease is increasing (Hartstichting 2019). To ensure that patients are not readmitted to hospital or suffer from a cardiac relapse, it is important that patients adhere to secondary prevention treatment. However, this is not as easy as it seems. The WHO (2003) states that poor long-term adherence of chronic ill patients to therapy is a tremendous problem. To illustrate, about 50% of chronic ill patients do not adhere to the longer-term care plan. The WHO (2003) argues that poor adherence causes negative health outcomes, decreasing quality of care and increasing healthcare costs. Therefore, it is crucial to develop care interventions that focus on prevention adherence.

Need for Prevention

To understand the purpose of prevention adherence for patients, in particular for those who suffered a Myocardial Infarction (MI), this chapter explores the importance and possibilities for prevention.
In 2019, approximately 35,000 people in the Netherlands ended up in hospital with a MI (Hartstichting, 2020). In the vast majority of cases, patients suffer from a MI, because the coronary artery that supplies that part of the heart with blood has been narrowed by a plaque of blood clots, cholesterol and calcium (De Hart & Vaatgroep, 2009). This is called arteriosclerosis. The infarction occurs when this irregular inner wall of the artery is torn, causing a final clot to block the passage completely. The development of arteriosclerosis can take years but does not always have to lead to problems. Many patients do not know they have the condition until troublesome symptoms arise.

Improving adherence to interventions for MI patients through secondary prevention and primary prevention for the patients' partner: positive return on investment, less re-admissions, higher quality of life and care.

After a MI event, the arteriosclerosis does not disappear on its own. If it has developed over multiple years, the risk of a (re)occurring event remains. However risk factors can be actively addressed to prevent deterioration, re-infarction and/or other CVD. There is a number of factors that increase the risk of narrowing of the coronary arteries. These risk factors can be divided into two different groups. The first group consists of factors that are not modifiable and the second group with factors that are modifiable (De Hart&Vaatgroep, 2009).

The non-modifiable risk factors are:

- Age: With age, the risk of atherosclerosis increases.
- Gender: men develop arteriosclerosis slightly earlier on average. In men, the risk increases after 35 years of age, in women only after the menopause.
- Heredity (genetic): In some families, high cholesterol and/or high blood pressure and/or diabetes mellitus are common.

The modifiable risk factors are:

- Smoking; causes harmful substances to enter the bloodstream. These substances can damage the vessel wall and thus increase the risk of atherosclerosis.
- Lack of exercise; Not exercising enough can be negative for weight, cholesterol level and other risk factors.
- Obesity; Obesity increases the risk of diabetes mellitus, hypercholesterolemia and is often accompanied by insufficient exercise.
- Cholesterol levels in the blood that are too high; can cause vascular wall damage and increased fat deposition.
- Unhealthy diet: too much saturated fat/salt;
- Diabetes mellitus; arteriosclerosis is more common in people with diabetes.
- High blood pressure; the pressure in the blood vessels is increased. This can cause a number of symptoms, including vascular wall damage.
- Prolonged negative tension (stress); Stress can increase the risk of developing cardiovascular disease. It can cause one to fall ill sooner and feel less energetic. People with stress generally also smoke and drink more.
- A previous heart attack;

The modifiable risk-factors can be actively influenced. This is why secondary prevention is recommended by health professionals. The aim of secondary prevention is to reduce the progression to full coronary thrombosis and therefore the (re)occurrence of serious cardiovascular events (Salvo et al., 2017; Piepoli et al., 2017). For secondary prevention, a combination of two treatments is commonly offered: pharmacotherapy and lifestyle changes. See figure 5 below for the current (simplified) prevention strategy.

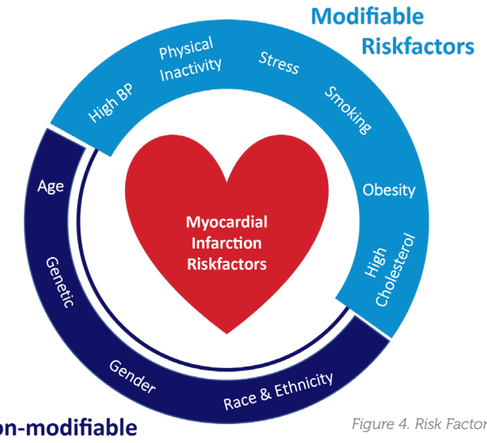


Figure 4. Risk Factors

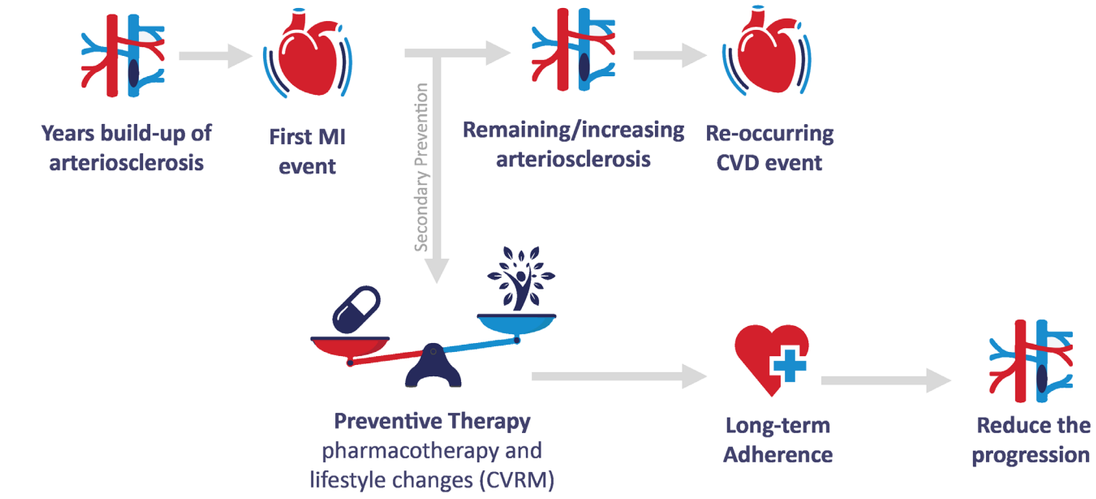


Figure 5. Current Prevention Strategy

Both pharmacotherapy treatment and lifestyle changes can prevent CVD events and/or delay the progression, but have some important differences (Brinks, Fowler, Franklin, & Dulai, 2016). These two treatment approaches are discussed below.

Pharmacotherapy

Patients are often given heavy medicines that are used preventively against deterioration of the disease. In many studies, this form of drug treatment has been proven successful in the reducing the risk of reoccurring events (Brinks et al., 2016). However, there are various adverse consequences associated with the use of the preventive medication. The medications often have severe side effects that can significantly affect the patient's life. As a clarifying example, the use of statins could increase the risk of developing diabetes by 46 percent (Cederberg et al., 2015). Also, the beta blockers keep the heart rate low, making (a.o.) physical exertion much harder for a patient. These side effects may cause patients to deviate from or stop their treatment, which results in negative health outcomes (Salvo et al., 2017). The pharmacotherapy is still the leading therapy within the prevention of CVD, but this often does not include patients' experiences about their medications. The main focus is on relieving the patient's heart rather than on the patient's illness experience.

Lifestyle Change as Medicine

In the current health care system, the drug therapy is the leading care model, but in recent years, more research has been done on the influence of lifestyle changes as preventive care. Lifestyle change is as important as preventive medication in decreasing the chance of recurrence of a CVD event such as an MI (Brinks, Fowler, Franklin, & Dulai, 2016). Numerous studies have concluded positive outcomes from lifestyle modification in patients with CVD. Yet, there is still much to gain in behaviour change as medicine. Several care professionals state that the decision to give medication to the patient is often made too quickly and easily, and therefore other possibilities such as behaviour adaptation is overlooked (Huber et al., 2011).

Paradigm Shift

This shift is already driven by several trends within the healthcare system. Aging populations, technological advancements, and chronic illness force the system to change (Levine, Malone, Lekiachvili, & Briss, 2019). Recent events like, for example, the corona pandemic has shown the importance of prevention next to medical treatment (Gommers, chairman Dutch Union Intensive Care, 2021). In order to ensure that the population care remains manageable, a preventive system must be developed. The trends and recent events are causing an acceleration in the ongoing paradigm shifts, altering the problem context. Two shifting aspects of the healthcare system relevant to chronically ill MI patients are described below: holistic care and continuity of care.

Holistic Care: Positive Health

Huber et al. (2011) pleaded for a change in the definition of the WHO of health: *"State of complete physical, mental and social well-being and not merely the absence of disease or infirmity"*. They state that the requirement of *'complete well-being'* could result in an increase of drug dependency and health risks, due to the emphasis on actively fighting the presence of disease and not on merely living a healthy life. That is why Huber et al. (2011) advocated a new definition of health: *"Health as the ability to adapt and self-manage, in light of the physical, emotional and social challenges of life"*. This definition describes the holistic view of health as a dynamic ability of humans to adapt and manage their own wellbeing and feel supported by the system in doing so. Within this new paradigm, the responsibility for care shifts more towards the to the patient and their social environment. Patients are progressively becoming (more of) a healthcare professional of their own health and are playing an active role within their own care(path). To enable this shift, the social context and care professionals should move towards guiding, coaching and teaching roles. Aiming to empower and enable patients to take control and be in charge of their own health in a positive way, decreasing reoccurrence of illness and re-admission.

"Our healthcare system is set up in such a way that we get sick and then go to the doctor, who solves the problem for us by giving us pills (...) Of course those pills work to some extent, but they don't fight the problem but the symptoms." - Diabetologist Prof. dr. Hanno Pijl in Skipr, 2019

It is therefore necessary that a shift takes place within the current healthcare system, with more attention being paid to the causes of the problem and to lifestyle changes. Within this shift, lifestyle should be used as an equivalent tool to medicinal therapy for secondary prevention.

Episodic to Continuity of Care

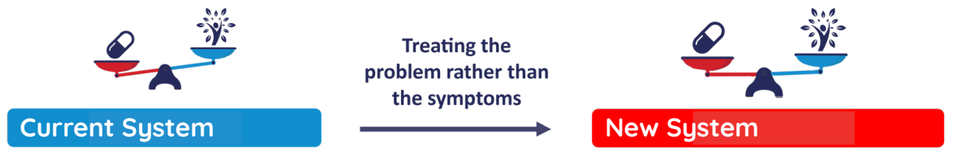
Alongside the holistic view of healthcare, another shift is taking place: from episodic to a continuum of care. Instead of providing incidental care when an illness occurs, and concentrating on the treatment of symptoms, there is a growing need to continuously address the cause of illness. The characteristics of both types of care are shown below (Koh, 2018).

For chronically ill patients, this continuous perspective on the care system means that they do not only receive care when they are with the professional, but that it flows seamlessly into the home context and beyond. To achieve this system, blended care is being pursued. This is a combination of offline and online therapy. Through this, the patient is educated, supported in his self-management and empowered to live a full life at any time in the course of his illness (Talboom-Kamp, Verdijk, Kasteleyn, Numans, & Chavannes, 2018).

Shift for MI patients

What does this shift mean for patients? As discussed earlier, there are two types of risk factors for cardiovascular disease: modifiable and non-modifiable. In light of the paradigm shift, patients will have to actively take responsibility in self-managing the modifiable risk factors during their long journey with chronic disease. In other words, patients must actively change their lifestyle and maintain it for the rest of their lives. They do not have to do this all by themselves, as they are supported by the healthcare system. Nevertheless, they are put behind the wheel and must actively decide which direction to take for their healthy physical and mental lives. In this vision, health is not seen as an end in itself, but as a means to live a qualitative life. To guide the patient towards a healthy life, the following 6 pillars are identified by Huber et al. (2011):

- Body functioning
- Mental functioning and perception
- Spiritual-existential dimension
- Quality of life
- Social participation
- Daily functioning



Episodic Care	Continuum Care
Reactive - for illness that are one-off that requires treatment with no follow-up	Proactive / preventive - for chronic diseases which requires extended care
Aims to a I leviate physical symptoms as they arise	Aims to address the cause of the disease
Low doctor- patient engagement	High doctor- patient engagement
Relies heavily on medication to treat symptoms of disease	Relies on diet, exercise and behaviour modification in addition to medication to manage symptoms of disease
Is ineffective and expensive in treating chronic diseases	Is time consuming but cost effective in treating chronic diseases
Usage of Technology is less. Patient and physician need not be in touch remotely to monitor patient health	Usage of Technology is high. Patient and physician regularly in touch remotely to test, record and report specific parameters monitoring health status.
Eminent Based Medicine is commonly used	Evidence Based Medicine- common
Essentially "fee-for-service" model of billing is practised	Sometimes "value based"/outcome based billinig is practised
Socio-ethnic-economic background or family history of patient is not considered for the assessment, therefore potentially affecting some diagnosis or treatment in a negative way	Socio-ethnic-economic background or family history of patient is considered for the assessment, therefore potentially affecting *some* chronic illness diagnosis or treatment in a positive way

Table 1. Paradigm Shift

The illustration below shows the lifestyle rudder. These are the lifestyle goals that have been drawn up, visualised in the form of a rudder on which the patient themselves can stand to determine his life path to a healthier life.

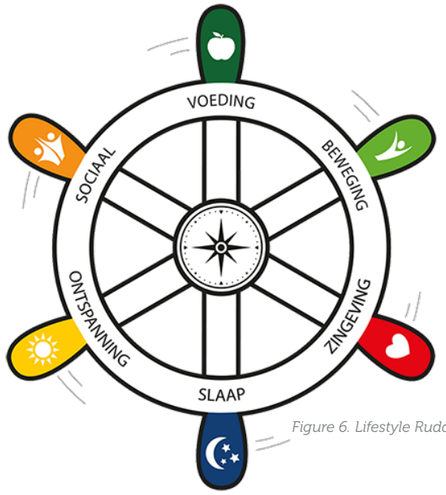


Figure 6. Lifestyle Rudder

By offering blended tools and interventions that allow the patient to adjust their lifestyle, patients are getting supported by the care system to live a healthy life in a holistic and continuous way. Central to these pillars are the patient's needs. Therefore, these tools and interventions should focus on what gives them the most intrinsic motivation; what is really important and what is most meaningful? Only then is it possible for a patient to adjust the modifiable risk factors and sustain the change.

Furthermore, not only living and maintaining a healthy lifestyle adds value to a quality life, but also has a significant effect on the course of the chronic illness. The changes decrease the risk of a reoccurrence of cardiovascular disease and readmissions to hospital. Below are shown four examples of the risk reduction as a result of lifestyle changes (Brinks, Fowler, Franklin, & Dulai, 2016):

Paradox

It is clear from the above that modifying risk factors prevents the recurrence of Myocardial Infarction and other CVD events (Brinks, Fowler, Franklin, & Dulai, 2016; Salvo et al., 2017, Piepoli et al., 2017). However, as mentioned earlier, MI survivors rarely are adherent to their lifestyle change therapy for the long term and relapse often in old habits (WHO, 2003; Janssen, Gucht, Dusseldorp, & Maes, 2012; Piepoli et al., 2017). This phenomenon, henceforth called the paradox, will be examined in the following sections. Here, their will be look into how patients who have been given a "second" chance do not do everything possible to prevent a recurring event.

Modification of risk factors reduces mortality and prevents recurrent cardiac events

MI survivors rarely change their lifestyle and relapse often in old habits

Exercise
25% reduction in mortality risk for CVD

Nutrition
20% reduction in the risk of recurrent CVD

Smoking
36% reduction in mortality risk

Depression
2.0 to 2.5 fold risk of recurrent CVD events and mortality

Causes Paradox

The paradox is affected by the motivation to adhere to therapy. According to Hanna et al. (2020) there are two types of motivation that influence each other and lead to the adherence: intrinsic motivation and extrinsic motivation. See the figure 7 below:

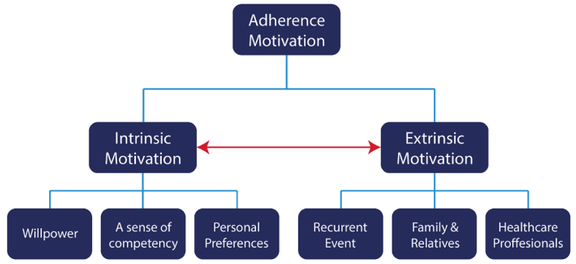


Figure 7. Adherence Motivation

According to Tjon-at-tsien, lifestyle-oriented GP specialized in CVD (2021) *"Intrinsic motivation is the most important determinant for lifestyle change and therapy adherence"*. As shown in the overview above, extrinsic motivation can be internalized and could be used to influencing the intrinsic motivation of the patient and vice versa.
In this study, the following two underlying causes of non-adherence to secondary prevention of lifestyle change were identified: decreasing intrinsic motivation and a lack of extrinsic motivation by the support system. These two barriers are outlined in the following paragraphs.

Decreasing intrinsic motivation

Behavioural change interventions for intrinsic motivation are an effective way to influence behaviour in the short term, but the effect wears off over time (Kwasnicka, Dombrowski, White, & Sniehotta, 2016). This often leads to a relapse into old patterns and habits. This also happens for patients who have had a Myocardial Infarction (MI). Just after a MI, patients are often highly motivated to adapt their lifestyle. However, this intrinsic motivation diminishes over time due to disliked behaviour and normalisation of the illness. To investigate what exactly is happening over time, two intrinsic motivation timelines are explored: micro motivation (day-to-day motivation) and macro motivation (longer period motivation).

Micro motivation:
It is difficult to say exactly what the reasons are for non-adherence in a micro-timeline (day-to-day motivation), because there are many different causes in time and contexts in which a relapse of behaviour can occur. This is illustrated by Kwasnicka, Dombrowski, White, & Sniehotta (2016) with a fictional example below. What we see is a clear wave movement of new and prior behaviour, with peaks and lows. Just before a peak of the old behaviour there is a risk of a relapse and after a relapse in a low of the new behaviour there is a risk that there is not enough motivation to create a new motivation/impulse to perform the new behaviour. To sustain the behaviour, a patient must be constantly aware of the risk of relapse, triggers and how to maintain the motivation to perform the new behaviour. This

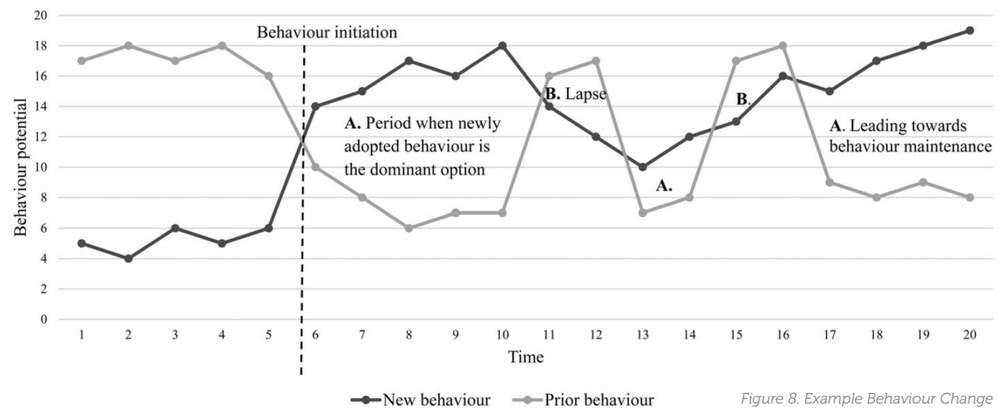


Figure 8. Example Behaviour Change

is difficult as many behaviours are unconscious since lifestyle often revolves around habits and routines. In addition, MI patients must modify their preferred habits and routines with *'medically prescribed behaviours'* to change their lifestyle (Hanna et al., 2020). As these behaviours are often perceived as less enjoyable or interesting, this results in less intrinsic motivation to initiate the new behaviours. Nevertheless, the more often a trigger and therefore a possible relapse is overcome, the easier it becomes to supress the prior behaviour. If this "repression" continues for a longer period of time, the behaviour becomes a habit and a part of life (Greaves, Reddy & Sheppard, 2010).

Macro motivation:
Condon & McCarthy (2006) show that after an MI, patients immediately try to make several lifestyle changes at once out of a need for control and fear, but often do not maintain this practice. They state that *"Individuals may become disillusioned, lose their motivation, and revert to old habits if unrealistic goals are set".* This is visualised in the following figure showing a plausible course of MI patients' motivation to change their lifestyle over time. In the short term, there is a peak in motivation, which decreases as the reality sets in that changing one's lifestyle is more difficult than expected. When there is less progress, it even becomes more difficult to maintain the motivation and after a while there will be a breaking point when the decision is made to leave the lifestyle changes for what they are and to stop trying.

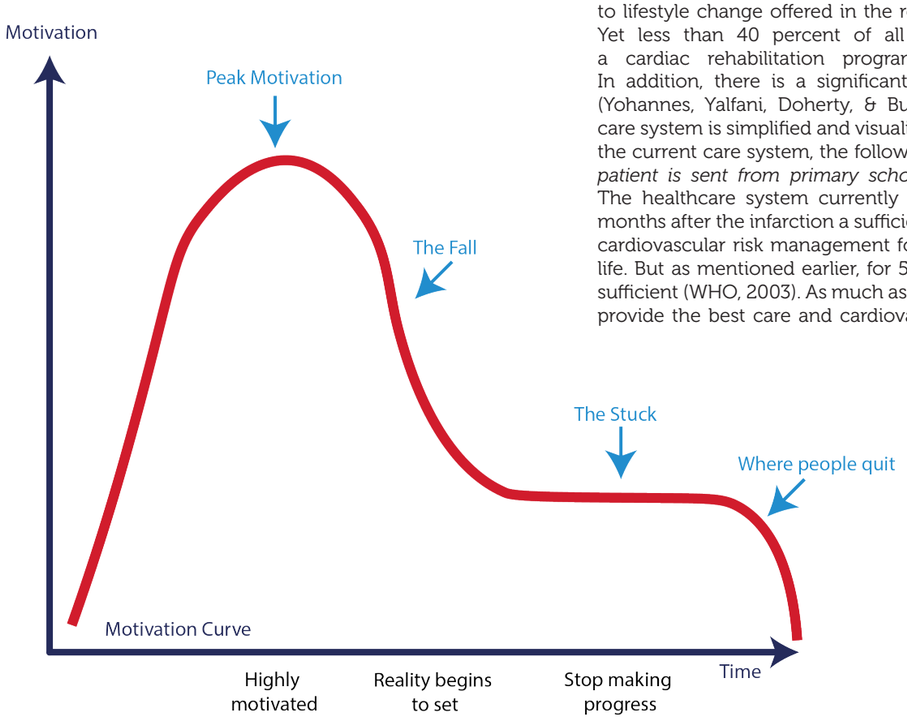


Figure 9. Longer Term Motivation Curve

The decrease in long-term motivation may be reinforced by the "normalisation of the disease" and the fact that patients often feel better after physical and mental recovery. Condon & McCarthy (2006) indicate that *'returning to the normal life'* is the end/most prominent goal of patients. Achieving this goal may cause a decrease of perceived necessity and relevance of the lifestyle change. Also, the actual effect of the implemented lifestyle changes is often not tangible. This can cause a downward macro trend in the motivation to adapt one's lifestyle.

For long-term adherence to lifestyle change, it is therefore important to stimulate a continuity of intrinsic motivation to prevent relapse and the abandonment of change over a long term period. Based on the theory of Hanna et al. (2020) this intrinsic motivation can be stimulated by the extrinsic environment. However, the current system is not designed to make use of this effectively. This will be discussed in the next section.

Lack of an Extrinsic Motivation by the Support System

The second reason for the low adherence is that after the infarction the patient experiences insufficient support and follow-up from health care professionals related to long term cardiovascular risk management Hanna et al. (2020).

Only in the first four months is intensive support in relation to lifestyle change offered in the rehabilitation programme. Yet less than 40 percent of all cardiac patients follow a cardiac rehabilitation programme (Harteraad, 2019). In addition, there is a significant risk of patient dropout (Yohannes, Yalfani, Doherty, & Bundy, 2007). The current care system is simplified and visualised in figure 10. To clarify the current care system, the following analogy is used: *"The patient is sent from primary school directly to university".* The healthcare system currently expects that in the four months after the infarction a sufficient basis has been laid for cardiovascular risk management for the rest of the chronic life. But as mentioned earlier, for 50% of patients this is not sufficient (WHO, 2003). As much as the hospital would like to provide the best care and cardiovascular risk management

throughout the pathway, to continue providing intensive care after the first four months is simply not possible for the hospital with the current system due to a lack of resources: time and money. This leads to a considerable gap between "acute and rehabilitation care" and "chronic care" in the long term.

To bridge this gap, the healthcare system currently assumes and demands that the responsibility for chronic care and lifestyle change in the private context be taken over by the social environment - often the partners and the patient. The patient's partner is generally willing to participate in the care, provided they are enabled to do so. However, they do experience a lack of appropriate knowledge, skills and professional support from a teacher (Hall, Sanford, & Demi, 2008). So they try to manage, support and motivate without the proper training and guidance from an appropriate curriculum. This results in a suboptimal self-created curriculum, which can lead to the importance of lifestyle change being overlooked. Step by step, attempts are being made in the health care system to close this gap, for example with the "*Gecombineerde Leefstijl Interventie* " (GLI). In reality, however, there is still a long way to go.

Conclusion

Many patients have difficulties sustaining the drive to change their lifestyle and suppressing their old behaviour over a longer period of time. The intrinsic motivation decreases over time. This motivation could be stimulated through extrinsic sources, like the partner and care professionals, but in the current system there is a shortage of long-term motivational and supportive care. A visual overview has been created and is depicted on the next pages to clearify the problem.
Currently, there is assumed that the social context, most likely the partner, takes over the care regarding lifestyle change in the 'chronic phase'. However, the partners are not sufficiently guided and educated by the care professionals in this process. As time goes on and the patient recovers, the importance and relevance for lifestyle maintenance decreases for all stakeholders. This raises the question for a possible solution direction: can the partner motivate the patient in such a way that they adapt and maintain their lifestyle on the long term? This question is explored in the next sections.

The picture below is a visual overview of the underlying problems of the paradox. It depicts in a simplified way 'the gap' and the identified causes concerning intristic and extristic motivation.

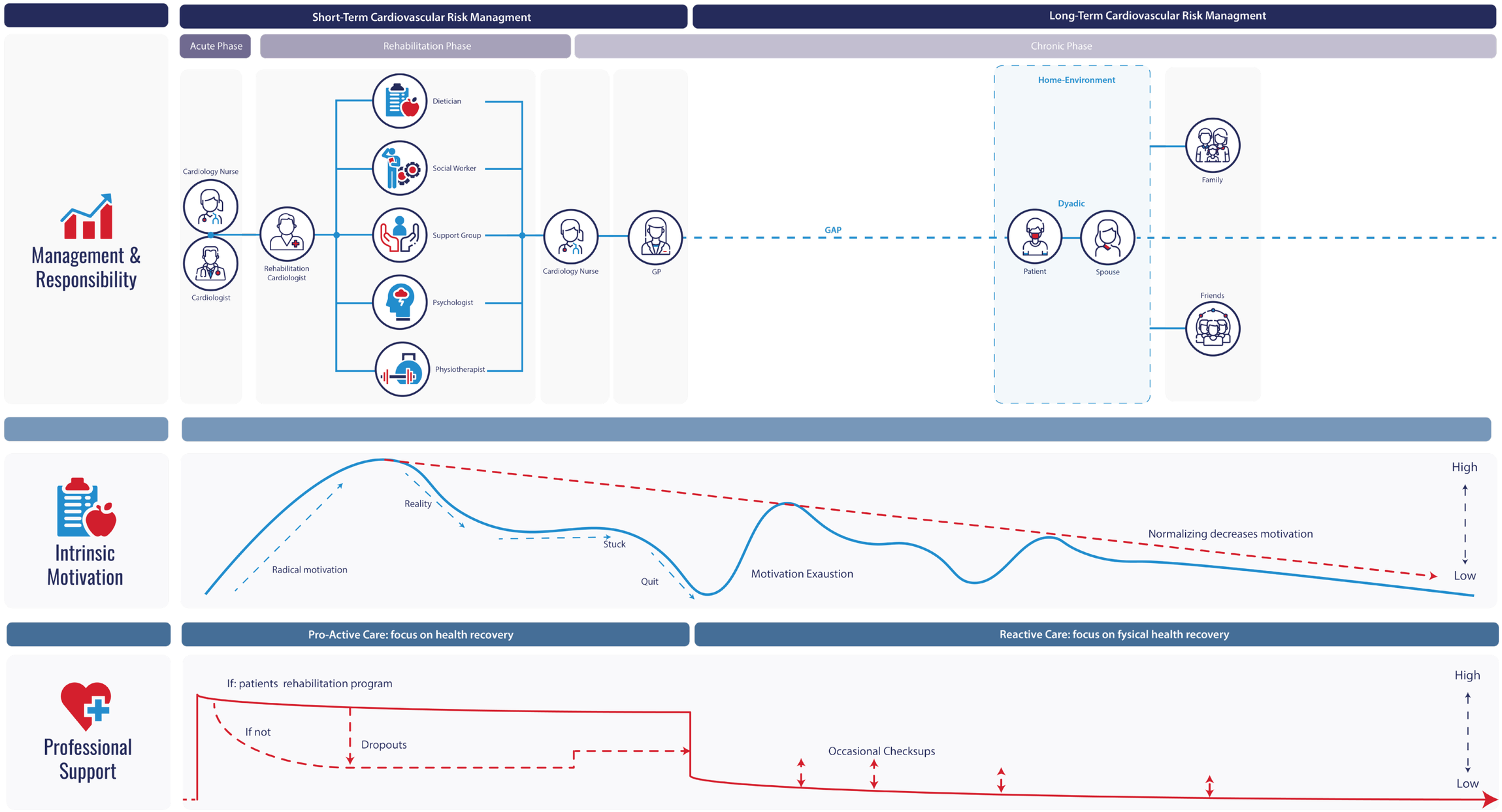


Figure 10. Current Problem System Overview

1.2 Dyadic Opportunity

In the previous section it was identified that the responsibility for long term cardiovascular risk management is placed almost entirely on the patient and their social context. How the partner can motivate the patient to adapt and maintain their lifestyle in the long-term management of chronic diseases will be examined in this chapter. To this end, there will be looked into self-management of chronic disease, how the partner can be used to influence patient behaviour for better health outcomes and how this relationship can be used for an blended eHealth intervention.

Self-management of Chronic Illness

In the new paradigm health is defined as *"the ability to adapt and to self manage, in the face of social, physical and emotional challenges"* (Huber, 2011). Here, the focus shifts from short term care of the patient to long term education. The patients will be empowered with skills to manage the chronic disease themselves.
Central to this paradigm and the management of the chronic illness is the common model of self-regulation (Leventhal, Phillips, & Burns, 2016). This is a conceptual framework that shows how humans react cognitively and emotionally to a health stimulus and threat, which determines their behaviour. This means that the perception of a patient's illness can influence his or her behaviour, either positively or negatively. Ultimately, it will translate into the expression of positive and or negative health behaviour.

The cognitive perception entails the beliefs of the patient regarding the following factors: identity, cause, control/cure, consequences, coherence, and timeline beliefs. These factors influence the coping strategy and therefore the behaviour that is shown. The cognitive perception in turn is influenced by the patient's emotions regarding the illness threat (anger, fear, worry) and vice versa. Various literature highlight the importance of illness perception on the adaptation, decision-making, maintenance of healthy behaviours and adherence to treatment (Figueiras & Weinman, 2003; Karademas, Zarogiannos, & Karamvakalis, 2010). Self-regulation interventions that change the perception of illness can influence the factors to be perceived as more positive and less of a threat, which could lead to better health outcomes (Sawyer, Harris, & Koenig, 2019).

This way of self-regulation is not only important for the patient, but also for the social environment. Studies have shown that the patient's perception of illness is influenced by that of the partner (Benyamini, Medalion, & Garfinkel, 2007). The partner's perception can enhance or undermine the adjustment process through supportive behaviour. According to Benyamini, Medalion, & Garfinkel (2007) the support relates in three ways with self-regulation: the illness perception of patients affects their expectations and evaluation of the partner's support; partner's own perception influences the expression of support; and incongruity between perceptions can cause an imbalance between expectation and expression of support. Therefore, it is important to assess and balance the interplay between the illness perceptions of both patients and partner for the best possible positive health outcomes related to the chronic disease. This interplay will be discussed in more detail in the next sections.

Dyadic Coping

"For the effective provision of care for chronic conditions, it is necessary that the patient, the family and the community who support him or her all play an active role."- WHO (2003)

This quotation suggests that for good chronic care, the patient's partner should be involved in addressing the patient's "health crisis". However, Eriksson, Wejåker, Danhard, Nilsson, and Kristofferzon (2019) argue that currently there is little or no attention, care and education for the partner in the current care system. Becoming chronically ill has a major impact on the continuation of the partner's life (Dalteg, Benzein, Fridlund, & Malm, 2011). Which in some cases even results in partners suffering from an increase in mental and physical health problems.

The interplay between partner and patient regarded chronic diseases is referred to as a dyadic coping, because of the entanglement of the partner with the chronically ill patient. In order to get a sense of the dyadic coping process and overcome the limitations of past reviews, Falconier & Kuhn (2019) combined several dyadic coping models that have emerged over the years into one integrated model, see the next page.

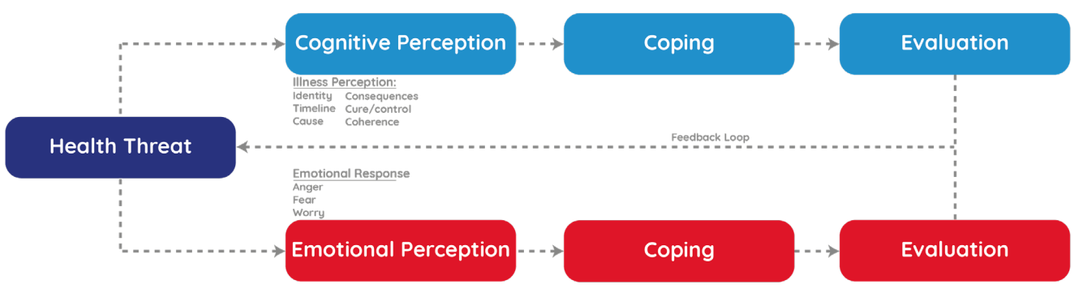


Figure 11. Common Model of Self-regulation

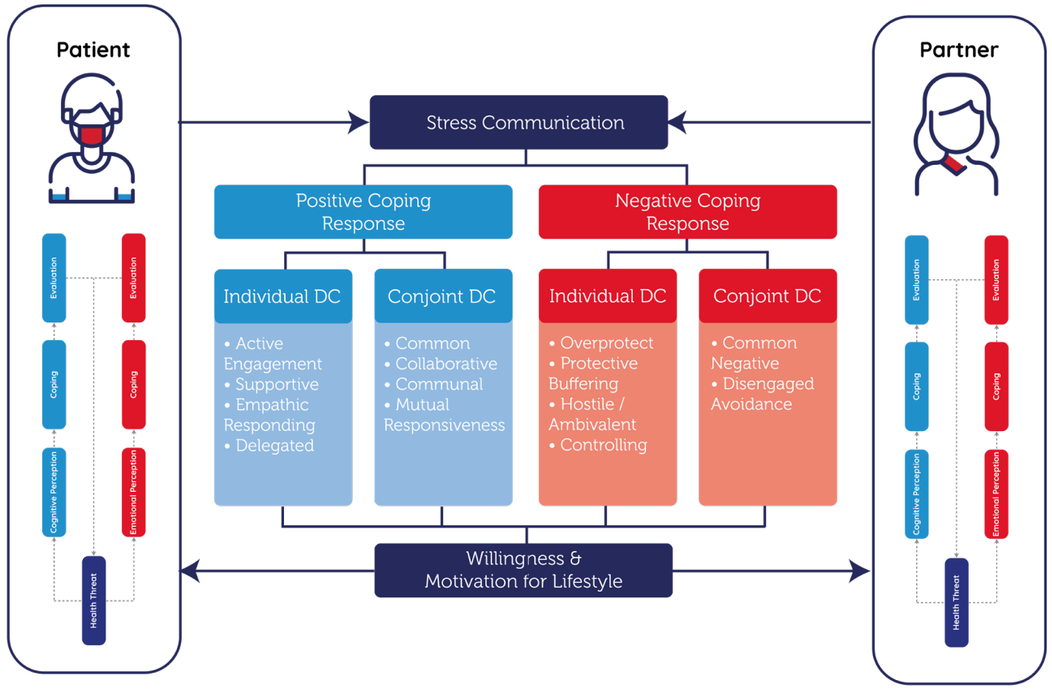


Figure 12. Integrated Dyadic Coping Model

This model focuses on the interaction (communication) between patient and partner concerning the chronic illness, as individuals and dyadic units. The model shows that stress communication can be coped with in two ways: the first is in a positive way and the second in a negative way. Within these different units, a distinction is made between an individually oriented approach or a 'we' approach. Next, it presents various strategies on how a partner and patient can respond to stress communication as individuals and as a dyadic unit.

Important determinants of which coping response is used are; the individual and dyadic needs, both congruence and incongruence of perceived support, illness perception and the dyadic relationship (Benyamini, Medalion, & Garfinkel, 2007; Karademas, Zarogiannos, & Karamvakalis, 2010; Rapelli et al., 2021). The use of positive coping strategies leads to improved functioning and well-being of the individual and the relationship, in contrast with negative coping where the opposite is true (Falconier & Kuhn, 2019). Through influencing positive coping, an opportunity arises to manage and direct the individuals and the dyadic relationship so that they, as individuals and together as partners, deal positively with the medical stressor, resulting in a balance that takes into account the needs of both and ensures positive health outcomes. This can lead not only to secondary prevention for the patient but, if used intelligently, also to primary prevention for the partner.

eHealth Box – Parallel Track

An emerging tool used for cardiovascular prevention interventions is eHealth (Saner & van der Velde, 2016). eHealth could increase the efficiency and effectivity of interventions by overcoming barriers of alternative interventions; financial, logistic and structural (Shaffer et al., 2020).
The Hart Long Centrum has developed an eHealth blended care path for this by introducing The Box. In the pathway, patients measure their vital parameters at home with the following 4 smartphone-compatible smart devices that are delivered in a box: *"a BP monitor (Wireless Blood Pressure Monitor; Withings), a step counter (Pulse Ox; Withings), a weight scale (Smart Body Scale Analyzer; Withings), and a single-lead ECG device (Kardia; AliveCor Inc)"* (Treskes et al., 2020, p.3). The measurement datapoints are forwarded to the LUMC and checked by the nurse specialist.
The abovementioned research on the partner-partner interplay provides an interesting opportunity to monitor 'psychosocial factors' (such as stress, illness perception, attitude and depression) in addition to 'vital parameters'. These psychosocial intervention strategies are not only able to influence the mental and physical health of the patient, but also the partner (Shaffer et al., 2020)

.

The patient's partner can influence the patient's health behaviour and motivation. Hence, a new perspective has been identified for The Box to stimulate beneficial healthy

behaviour change; using positive communication and support to influence the illness perception of patients and their partner. This offers the opportunity to create a parallel track, next to the current care pathway, in the form of an eHealth intervention for the partner, complementing the existing The Box innovation. This could lead to the following three benefits:

First of all, an eHealth intervention in the form of 'a box' or an addition to The Box for the partner can ensure that the partner receives the necessary tools and that behaviour is guided to provide positive chronic care to the patient, which stimulates healthy behaviour. Together, partner and patient could be directed towards positive behaviour (figure 12) that is improves the adherence to lifestyle change resulting in secondary prevention for the patient and primary prevention for the partner. Which, ultimately leads to less care expenditure, less re-admissions because of recurrent events and a higher quality of life and care.

Second, the eHealth intervention offers the possibility of profiling the dyadic relationship and personalization. Rapelli et al. (2021) state that by identifying the used dyadic coping strategy it is possible to identify individuals and relationships who are most at risk of a decreased wellbeing and functioning. Therefore, psychosocial data could be used, for example, to identify the partners and patients who have more difficulties in coping and are therefore more at risk and to provide them with tailored care. In addition physical data of the partner could be used to get a better understanding of the patient's 'health context'.

Third, an eHealth intervention involving the partner could benefit from integrating the partner's gut feeling. Because the partner and the patient are in a dyadic (lifestyle) relationship, the partner perceives different social cues that may not be visible to the patient because they are gradual or unconscious (e.g. depression, less exercise, watching more TV). In combination with vital parameters, this could generate valuable health information for care professionals to create more personalized treatments.

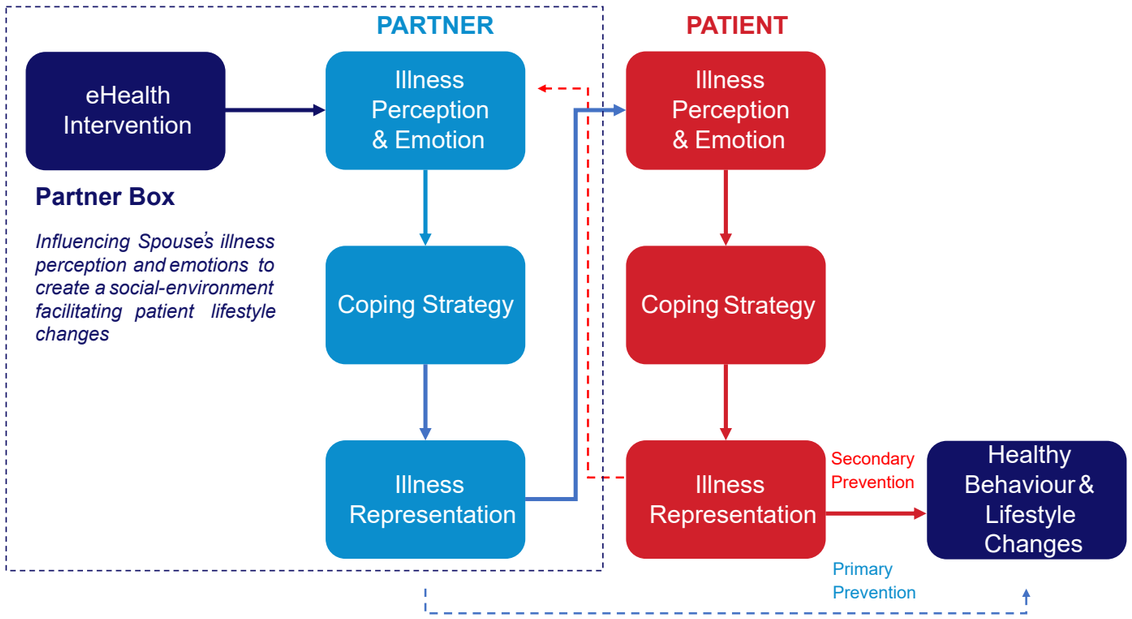


Figure 13. eHealth Intervention Opportunity Partner Box

2. EMPATHIZE

In order to develop an effective eHealth intervention as Product Service System, it is crusial that it matches the needs of the user (Saner & van der Velde, 2016). To achieve this, the (latent) needs of the patient and the partner should be identified so that "The Partner Box" can be adapted accordingly. Therefore, this chapter will explore the experiences and needs of the partner in relation to the patient.

2.1 The Dyadic Experience

This section explores what is needed for the eHealth intervention to positively influence the partner in adjusting their disease perception and expression in relation to lifestyle change. As just mentioned, for the intervention to be successful, it is very important that it meets the needs of the patient and the partner. For this purpose, a new perspective is introduced that shows why a 'Box' is required that is not static like the current intervention, but dynamically changes over the long term linked to the needs of the partner and patient.

Grieving Cycle - Partner and Patient

Many chronically ill patients and their partners, react in a grieving way to the abrupt change of the health situation after the medical diagnosis and lifechanging event (Kübler-Ross, 2014). The type of grief that comes with chronic illness is a complex individual experience, which can cycle again each time a new problem/barrier presents itself. According to Kübler-Ross (2014), patients and partners that mourn their past lives, need to work through the following stages:

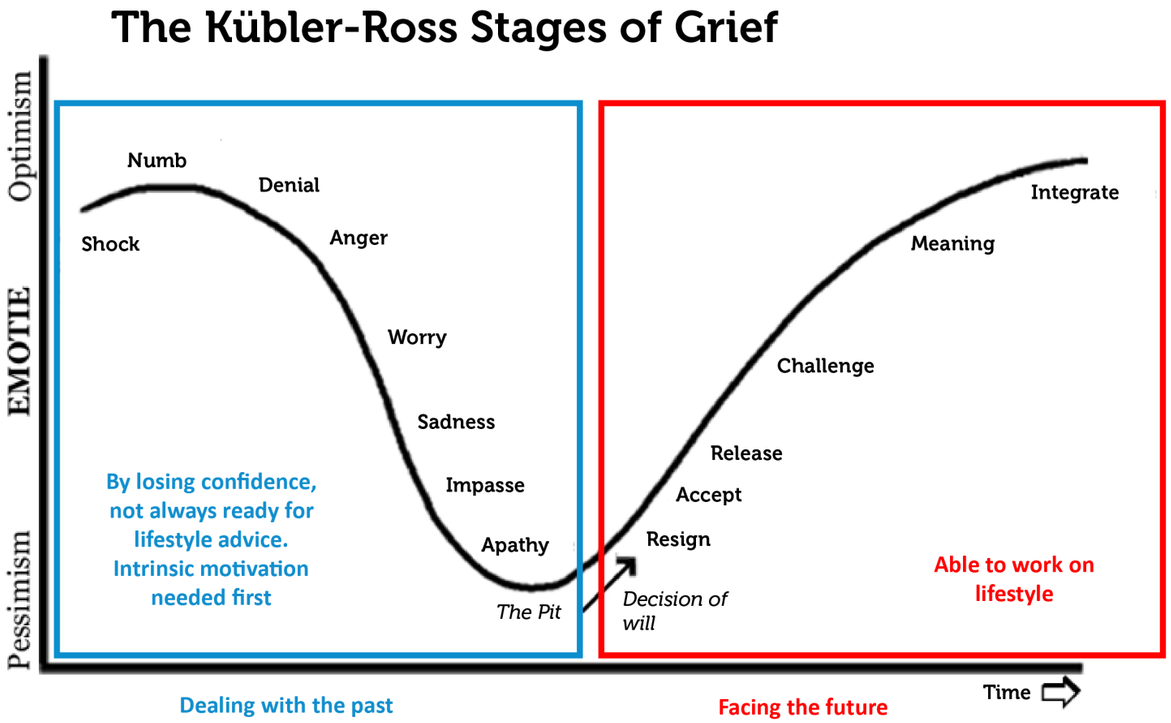


Figure 14. The Kübler-Ross Stages of Grief

As just mentioned, each patient and partner go through their own cyclical process and has their own experience. This would mean that there is a spectrum of coping. This is actually a logical disclosure because the life changing event can differ per case: there is a difference between a partner that needs to resuscitating the patient, compared to a partner driving the patient to the doctor with some chest pressure.
The grieving cycle shows two main phases: The first phase is one of processing 'the past' and 'the previous way of living' of the patient and the partner. In this phase, the mental impact of the event must be processed and letting go is the subject of focus. In the second phase, the patient and partner look to the future again. This is the time to work on a plan for the future, including lifestyle changes. This means that looking to the future is something that cannot be forced, but must be worked towards over time by first addressing the mental and physical processing of the event.

For some this process of grieving can completed faster than for others. Even among couples, the process and pace differs. At present, the current care system takes little account of people's individual differences in how they cope with the event in the long term. The current care system is set up to physically integrate patients into 'normal life' as quickly as possible. As mentioned earlier, the patient is sent to university without the proper education, they are given an emergency course in cardiovascular risk management in four months. Yet, they still have to cope mentally with the event. This could result in less engagement during long term lifestyle adjustment. For the partner, it is even more difficult to participate. They are even less involved in the professional care, are responsible for their own coping with the event and also have to supervise the coping process of the patient.
Because of the goal of lifestyle change, it is interesting to see how an intervention such as The Box could be used to influence this curve in order to guide the partner and the patient as best as possible, depending on their needs. Initially, this will involve working on coping with the infarct until a point of will is reached: *"and now it's time to adjust our lifestyle for our future"*. At this point, the intervention will focus on encouraging the individuals to change their lifestyle. To tailor the intervention to the patient and partner, their exact needs will be explored in the next section.

Researching the Patient-Partner Experience

Introduction

Each patient has a unique experience that can be visualised in a journey (Simonse, Albayrak, & Starre, 2019). The same principle applies to the experience of a patient's partner. The previous chapters have shown that there is an interplay and interdependence between the patient and the patient's partner in dealing with the adjustment process after a heart attack. Furthermore, each individual goes through their own grieving process after a life changing event such as transition from a 'normal life' to a chronic illness. Within process after it has been shown that the needs of individuals change over time.

There is already a considerable amount of research into the MI patient's experience and needs, as this is often central to the medical system. But the partner's experience and needs are often still under-researched (Salminen-Tuomaala, Åstedt-Kurki, Rekiaro, & Paavilainen, 2013). Therefore a research is performed to explore and visualize the dyadic process of the patient-partner experience of adjustment following a MI.
Because of the dyadic intertwined nature and the corresponding time line, the adaptation trajectory of the patient is used as a theoretical framework to create an adaptation trajectory for the partner. Central to this framework is the second chapter of *"the Illness experience"* by Morse and Johnson (1991). They broadly describe the adaptation journey that an MI patient goes through, taking into account the variation between different patients and experiences. The following figure shows the simplified framework of "Regaining Control", which is the central theme of the patient's adaptation process.

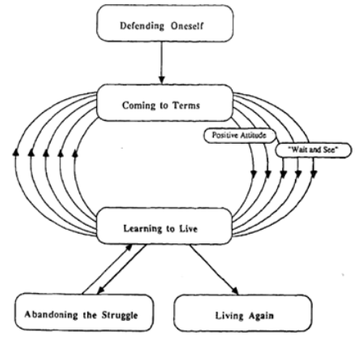


Figure 15. The Process of Adjustment Following a MI

To find out more about the partners' experiences and the relevant themes, the following sub-research question was formulated for this study:

"What is the process of adjustment following a heart attack of the partner of a MI patient?"

Method

Data collection:
In this research, two steps of data collection are performed: 1) online stories from partners 2) in-depth semi-structured interviews with partners. Below is a description of how the data was collected in each step:

1) Online Stories of partners (73)
Jamison, Sutton, Mant, & De Simoni (2018) state that for qualitative research on patients' and caregivers' experience regarding secondary prevention adherence, online forums

are an appropriate source of data. Therefore, online stories of partners were collected from the foundations' websites related to heart attacks. The following table shows the inclusion and exclusion criteria for data collection:

	Inclusion Criteria	Exclusion Criteria
Author	Partner of a patient	Not a partner of a patient
Related to medical condition	Myocardial Infarction	Other conditions
Situation	Lives together with the patient	No longer lives with the patient
Foundation	Related to heart diseases	Not related to heart disease
Country	Western countries	Other countries

Table 2. Inclusion/Exclusion Criteria Stories

Due to the availability of public messages from partners on forums and the time available for this project, a total of 73 online stories were collected manually. For this purpose, the stories were first read carefully to verify their relevance to the study. The table below shows the distribution of the sources where the stories (experiences) were collected.

Country	Foundations	Stories collected
United Kingdom	British Heart Foundation	N=21
United States	American Heart Association	N=40
Netherlands	Harteraad	N=12

Table 3. Distribution of Story Sources

2) In-depth Semi-structured Partner Interviews (3)
In order to get in-depth insights in the process of adjustment and experience of patients and partners, inductive qualitative semi-structured interviews are performed (Braun & Clarke, 2013; Patton, 2002). The selection of participants for these interviews is based on a key informant strategy. This selection of key informants consists of *"people with great knowledge or influence that can shed light on the topic"* (Patton, 2015). Participants were approached through various online media and asked if they were willing to share their 'expert' perspectives and experience in an interview. The following table lists the criteria on which the participants were selected:

	Inclusion Criteria	Exclusion Criteria
Patient Age	45-70	<45 or >70
Condition Patient	Experienced an MI	Has not experienced an MI
Lifestyle Change	Partners who have made or attempted to make lifestyle changes together with the patient.	Partners who are not willing to adapt their lifestyle for the patient.
Living Condition	Lives together with the patient	No longer lives with the patient

Table 4. Inclusion/Exclusion Criteria Interview Participants

The table below gives an overview of the participants included in the interviews. Due to the corona pandemic, it was difficult to conduct a physical interview. Therefore, it was decided to do this via video calls on Microsoft Teams. The advantage of this is that a clear recording can be made, allowing more implicit social cues to be picked up by the interviewee during the analysis of the data, such as facial expressions of the participant (Patton, 2002). After the digital interviews, the audio files were transcribed and anonymised.

Partner	Age & Gender	Contact	Context
1	60-65, Female	Video call	Partner has experienced an MI
2	55-60, Male	Video call	Partner has experienced an MI
3	50-55, Male	Video call	Partner has experienced an MI

Table 5. Overview Included Participants

Ethics
The study was performed under the ethics code of the Human Research Ethical Committee (HREC) from TU Delft and the Data Steward of the IDE faculty. In order to protect the safety and privacy, the data collected is anonymised and therefore not traceable in order to protect the contributors.

- For the online stories (1), only public published data and stories are used from the forums. This data will also be anonymised.

- And for the interviews (2), permission has been requested to make use of the anonymized data. This will be clearly indicated beforehand with the signed a consent form. In addition, there is no burden for the participants. During the study, mainly questions about their experiences as 'experience experts' are asked. Should it happen that a participant does not want to answer a question or wants to withdraw form the research, he or she has every right to do so.

Data analysis
After collecting the in-depth insights with the online partner stories and the semi-structured partner interviews, the Grounded Theory Methodology (GTM) from Birks & Mills (2015) was applied to analyse the data. This method consists of *"systematic, yet flexible guidelines for collecting and analysing qualitative data"* (Charmaz 2006, p.2). The data is manually analysed using the tool ATLAS.ti 9. The following steps of the GTM method are used in the analysis:

Step 1: Data merging
All data is merged into one document. Here, the three transcripts of the interviews are combined with the 73 online stories.

Step 2: Data coding
Each section of text is assessed for its relevance to the study. An effort is made to examine the section objectively to see if it is relevant to the partner experience. These relevant sections will be marked with a corresponding word or short phrase (code) referring to an objective insight of the section. This resulted in 423 codes.

Step 3: Code clustering
The next step is to cluster the codes. The codes are critically and analytically compared between and within categories. With this, 14 clusters have been created.

Step 4: Cluster labelling
Once the clusters are established, an overarching title will be added to elaborate on the coding content of that category. The categories will be more abstract because of the interpretation of the initial codes' meaning.

Step 5: Theory construction
The final step is to construct a theory based on the links between the different categories. This step was also followed, but the clusters were linked in a different way as usual in the GTM method. In this research, journey mapping and the framework of Morse and Johnson (1991) were used to construct the theory. Here the clusters are thematically compared to the phases of the patient experience framework. Then a process journey was visualised for both the partner and patient based on the patient journey method (Simonse, Albayrak, & Starre, 2019).

The theoretical journey map represents the final iteration of the analysis which is used to answer the research question. In the next section, the results of the qualitative research (GTM) and the dyadic adjustment process following a MI are presented.

Results

Below are the 14 categories (in random order) that result from performing the GTM. Here, the title of the clusters are shown including the amount of codes between the brackets. In addition, there is a short description of what the categories represent.

The following categories are developed:
- Abrupt Change of Life (30)
- Trajectory of Acceptance (32)
- Emotional Loneliness in the Parallel Partner Journey (40)
- Adjustment to the (New) Normal (41)
- Dealing with Mental Recovery of the Patient (24)
- Well-intentioned Loving Care and Support (42)
- Regaining Trust in the Patient's Body (31)
- Rebalancing the Relationship (27)
- Re-establishing Control through Empowerment (19)
- (Self)Care for the Forgotten Partner (23)
- Holding on to Future Perspective (27)
- Adapting to Changed Patient Personality (8)
- Coping with Uncertainty of Life (42)
- Need of Support for the Support (35)

The content of the categories is discussed on the next page. These categories provide insight into the needs of the patient's partner during the adaptation process. To see the result immediately: the result of the partner process is visualised on the page 34 & 35.

Abrupt Change of Life (30)
This category describes the impact of the infarction, which often happens unexpectedly *"life changed overnight"*. From one day to the next, the partner almost lost their loved one (faced with his/her mortality) and the patient's image changes from normal to chronically ill. This shock is dealt with by initially activating the survival mode, whereby the event does not yet really sink in. The severity of the shock varies from one couple and MI to another.

Trajectory of Acceptance (32)
Here, the (long) recovery process is described. It mainly refers to the mental process of coping with the changes step by step *"acknowledge the changes. Turn the knobs a little bit every day"*. The partner, together with the patient, must find the balance for their new life and say goodbye to the old. This is where time is the most important factor that heals the most.

Emotional Loneliness in the Parallel Partner Journey (40)
The partner is in a difficult position; besides the fact that they have to deal with the emotions of the patient connected to the infarction, they also have to deal with their own emotions. In addition, life goes on and the partner often has to fill in the gaps. This often causes the partner's feelings to fade into the background. *"There are so many emotions going on in my head and heart. I know he has gone through major trauma and that part was so scary but this emotional part after is sooo hard"* The uncertainty of how the partner can and may express themself to the patient results in a feeling that they cannot/should not express their emotions and that the partner(as not being a patient) needs to stay strong. This results in a feeling of being alone.

Adjustment to the (New) Normal (41)
This category is about normalising the disease. In time, when the emotions and physical problems subside, a new normal is established. *"In the beginning, you find that very scary. When you're actually sitting on the sofa and suddenly your wife collapses. From a normal person to someone who is very tired [...] Then her motor really slows down. And yes, in the beginning you have to get used to it. But now I actually find it very pleasant that we are taking it a bit slower."* A new balance is found in the life and lifestyle of the patient and his partner in what is possible. Slowly, they can look with certainty to the future again.

Dealing with Mental Recovery of the Patient (24)
In addition to dealing with their own emotions, the partner must also deal with the patient's emotions. This can sometimes be a heavy burden with the partner having to deal with blame, anger and depression. These can be strong emotions which can result in a deterioration of the relationship. *"How do I deal with the emotions from him saying he is ok to blaming me for being there. I feel like I walk on egg shells all the time."* This can make it difficult to stay positive, process one's own emotions and support the patient as well.

Well-intentioned Loving Care and Support (42)
This category is about the support that the partner provides to the patient. The partner is in most cases very willing to support the patient. This can be done in different ways: functionally and emotionally. But it is difficult to determine for the partner what the right way and right help is. *"How have others figured out the right level of support for your loved..."* In addition, it can be experienced as undesirable as overprotection or undermining if it does not match the needs of the patient.

Regaining Trust in the Patient's Body (31)
Due to the impact of the infarction, both the patient and the partner have lost confidence in the patient's body. The trust has to be regained. This can result in a lot of anxiety for the partner. *"My experience was utter terror at the thought of him at home with me alone. I even bought a baby monitor so if I left him on his own I could hear him. I woke up every hour or so at night to check him. For month we never ventured more than a few feet from each other."* Especially since the partner cannot feel what the patient feels and has to rely on the patient's feedback and own interpretation.

Rebalancing the Relationship (27)
Because the relationship between partner and patient changes abruptly. At first, the partner takes over a lot: *"I was the only one holding the whole house of cards together"*. But when the patient is capable of more, a new balance will have to be found. This has to happen within different relational aspects: domestic roles, sex life and intimacy, perspective (patient or loved one) etc. This can lead to friction, and may take time. Good communication is especially important: *"Make changes in your loved one's behavior negotiable. The patient is probably just as bothered by it as you are"*.

Re-establishing Control through Empowerment (19)
The partner has to deal with a lot of uncertainty. There are various strategies by which they try to empower themselves: self-education, seeking assurance from healthcare professionals, participating with the patient, doing everything possible to improve the health situation. This creates a sense of control. *"I'm desperately trying to get as much information as I can regarding diet [...] I must be doing something right he has lost over a stone in a week he's never been a smoker and was very active but is over weight ..... my journey for knowledge has begun"*.

(Self)Care for the Forgotten Partner (23)
This is a category that deals with a partner's guilt when thinking about themselves. *"He has the right to be scared and nervous and I feel guilty at the same time for feeling overwhelmed"*. As a result, they tend to fade into the background. Over time, the partner learns that it is important to take care of themselves so that they can take care of the patient *"Slowly but surely I regained the space to think about my own dreams: a big family. We made good arrangements about the foster children and went for it, despite his illness"*. However, there remains a feeling that they are not supported enough in their own needs.

Holding on to Future Perspective (27)
This category is about positive future prospects. This is an important point of reference for the partners. Without a future perspective, everything would collapse. This stimulates and motivates them to work towards something together, and to enjoy each other. *"It's encouraging to know that lots of people have gone through this and have come out the other side, and are enjoying their lives as a result"*.

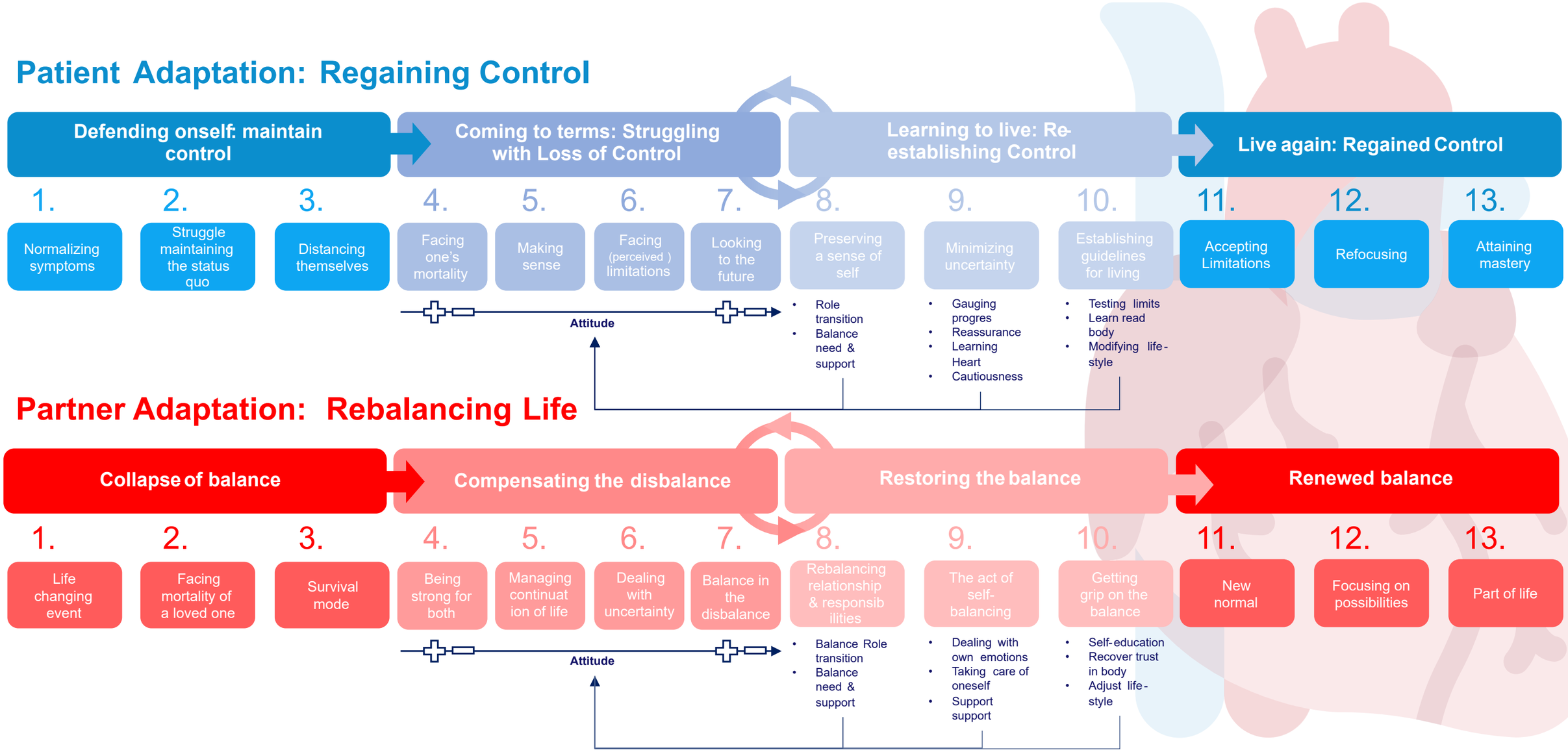
Adapting to Changed Patient Personality (8)
The partner has to deal with a change in the patient's behaviour. This can be negative and positive. Sometimes the patient's behaviour changes so much that the partner does not recognise him or her as it was before the attack. *"He has gotten a lot better but he has changed a lot"*.

Coping with Uncertainty of Life (42)
Uncertainty plays a major role for the partner. After the confrontation with the infarct, the course of life is uncertain. Confidence has to be rebuilt, which depends on medical assurance, physical and mental feedback, prospects, time, hope, attitude and stability. *"Our first few months at home have been SCARY, because we don't know what to expect. We assumed every headache was another infarction and don't know what's around every corner. But you know what, that's okay. Quite frankly we are still scared. But the best you can do is take your medicine, do the therapy, push as hard as you can to stay on the right path and PAY ATTENTION TO THE SIGNS and act accordingly"*.

Need of Support for the Support (35)
There is a greater need for support from the partner than what they are currently receiving. At the moment, they are expected to support the patient, but they themselves receive little to no guidance on how to do so *"But what I would say is, I think the partner should have a bit of support in what he should do, because I mean, it's not always sure what he can still do and what he should do, of course, because the most important thing is to see what is still possible."* This support could come from the medical professionals, family and peers.

After the categories have been determined with the GTM, they are thematically compared to the framework of the patient's adjustment process (Morse & Johnson, 1991). The main themes of the patient experience and the timeline outlined in the study are considered as achorpoints of the framework. The content used for the patient experience and how it relates to the partner experience is visualised in Appendix A. The comparison between the identified categories that play a role in the adaptation process of the partner and the patient experience, revealed that the most important overarching theme for the partner is to rebalance life after the patient's infarction. The result is visualised in a journey map based on patient journey method (Simonse, Albayrak, & Starre, 2019). The result of this journey map is depicted on the next pages.

The Dyadic Experience



The content of the partner journey per step is depicted in Appendix A. These are based on the various categories formed by the GTM and the framework of the patient journey.

Figure 16. The Dyadic Experience

Discussion

To answer the sub-research question *"What is the process of adjustment following a heart attack of the partner of a MI patient?"* The themes that emerged from an interview and online stories are matched with corresponding themes from the patient journey. Based on this, 4 phases have been identified that play a significant role in the partner's journey of the adjustment process after the infarction of the patient: (1)Collapse of Balance, (2)Compensating the Disbalance, (3) Restoring the Balance and (4) Renewed Balance. Within these phases, the relevant themes that correspond to the needs and interests of the partner have been identified regarding the adjustment process of the partner. Important facilitators in this journey to balance are: feeling of control over the illness, positive future perspectives, balancing the role of support, regained trust, and an equal emotional and physical relationship.

The results of the research corresponds well with the study by Salminen-Tuomaala, Åstedt-Kurki, Rekiaro, & Paavilainen (2012). The coping pathways described in this study fit well with the themes found in the research. They argue that there are positive and negative pathways that the partner can go through to regain balance with the illness. Additionally, they state that the 'coping route' is depending on the patient's illness perception and the physical and mental resources that they possess (attitude, mood, motivation, skills, knowledge, tools). Also, the partner's physical and mental resources are able to impact this route. These factors are also important in the drafted journey, because they determine how often a partner goes through the loop, moving between compensating the imbalance and restoring the balance.

This shows that, it is important to identify how the process of balancing can be supported by means of an intervention that guides the process in a positive direction so that coping takes place in the right way and the needs of partner and patient are met. In order to do this correctly, it is important to look at the phase in which a partner and patient are in order to offer the right intervention in the right phase. In addition, it is interesting to find out what journey a partner and/or couple goes through in order to be able to predict their attitude to the adjustment and to determine who needs extra help and support from a medical/social point of view.

Limitations

There are several limitations to the research. One of them being the use of online stories. They rely on the experiences of people who posted (about) them online. This is a specific group, who feel the need to share their experience or to read people's experiences. This can limit the number of different partners. However, this may be the most interesting group, as they apparently have needs that are not currently met by the medical system and seek answers from peers.

The main limitation of the interviews is the small participant sample of the interviews, the findings should be compared with a more extended sample to test the validity of the results. However, by combining the data with the forum data, it ensures a higher degree of reliability. Furthermore, the main goal is to find out the themes that play a role in the course of the adaptation process and this has been achieved.

Conclusion for PSS

The preceding research has identified relevant insights into the needs of the partner in the dyadic relationship with the patient. These insights show that an eHealth intervention for the partner should be dynamic and change over time in line with changing needs of balance during the adaptation process. Within the scope of the main research question: *"How can partners of chronically ill patients, that suffered from a MI, provide effective and positive support for the patient to maintain long-term preventive lifestyle changes by means of an eHealth innovation linked to The Box?"*. The following main needs (questions) of the partner have been identified in which an eHealth intervention would be able to support: How can the partner support the right way, how can the partner themselves be supported in the process and how to strive for a relationship where the right balance between 'patient' and 'loved one' is achieved during the adaptation process. The eHealth system can fulfil the following roles in this:

Relation Therapist

To meet the needs of the key stakeholders, the eHealth could act as a kind of relationship/interaction therapist. This therapist determines what stage the partner and patient are in by observing the psychosocial and physical factors. These factors can then be used to identify the needs at a particular time and the eHealth could then respond to meet those needs. It is essential that the partner understands his own and the patient's needs, as these can change from one day to the next as a result of the infarction. Uncertainties that the partner suddenly has to deal with are, for example: How do you ensure that your partner still feels 'normal' and yet thinks about the long-term consequences of their behaviour? How do you deal with your own worries regarding? How can I get our life back into balance. I am willing to support, but how can I help? When do I support not enough, when do I support to much? How to switch between being a partner and a carer? Can we do the same things as before?

Professional Insights

Besides being a relationship therapist, an intervention could provide an understanding of the dyadic relationship and experience for the healthcare professional. The system could create certain risk profiles of the individuals and the dyadic relationship, for example by monitoring the experience: how many setbacks do people have to endure, the attitude they have towards the future, how they feel during the process. Based on this, an estimate can be made of how likely they are to change their lifestyle or stop trying to change their lifestyle. Do they need more motivation? Does a health professional need to intervene professionally? This allows a care professional to gain more insight into the adaptation process behind the couple's front door and provide tailored support.

Proactive Empowerment

Furthermore, the system can steer towards increasing the resilience of partners by providing more certainty about the adaptation process and guidance on self-care and self-efficacy. The system will not only act reactively, but can also provide proactive guidance. This can be done by positively influencing and directing the adjustment process in such a way that it proceeds 'faster and better', so that the stage of effectively implementing lifestyle changes is reached sooner.

After having been inspired by and understanding the needs, challenges and problems in the patient-partner dyadic relationship through gathering data and insights, it is time to imagine new opportunities and generate novel and fruitful insights for the eHealth intervention solution that guides and stimulates a partner in supporting the MI patient's motivation management to long-term lifestyle changes and how to maintain a balanced relationship.

3. IMAGINE

In this chapter, creativity and imagination are sparked to address the problem. The solution space is enlarged in order to find fruitful and new solutions to the problem. In doing so, it is reframed into relevant fields and future possibilities are considered. The resulting insights are used to determine an innovative future vision for the Product Service System.

3.1 Reframing

Frame

According to Dorst (2015, p.5) "*design contains a process of thinking around the paradox rather than confronting it head-on*". He argues that a design problem, by its very definition, is stuck in its own context. Meaningful paths to move towards a new solution can be found by looking at the problem through a new frame in a different context. Based on this, Dorst (2015) developed a design method of which the themes, frames and future steps are used in the imagine phase of this research project. In the case of MI patients, the most important factor is intrinsic motivation, which affects the problem of long-term adherence to lifestyle change. The framework, used in this project to address the problem, is therefore: *'How can a partner be guided to stimulate a patient's intrinsic motivation to commit to long-term lifestyle changes and have a balanced relationship?'.*
With a design-driven approach, a pragmatic study is conducted within domains relevant to the created frame. For this purpose, the frame is reframed into the various 'performance-driven' contexts in which people are successfully encouraged by a 'supporter' to build up intrinsic motivation. The domains considered in this study are (1) Topsport training and (2) Addiction recovery. First, in-depth knowledge will be gained regarding the framework in the new domain, after which the knowledge will be interpreted in the context MI Partner-Patient Intervention. The new insights gained by reframing will be collected and used to imagine solutions for the long-term adherence problem of MI patients and partners.

Supporting lifestyle change as Topsport training

Top athletes do everything in their power to reach their ultimate goal. This section focusses on how athletes maintain the motivation to dedicate their lives to working towards this. The goals differ for every athlete: some aim for Olympic gold, others want to make the step to the top. But what they all have in common is that they strive for a goal by committing to an intensive training programme lasting many years. During this program they are guided by professionals who encourage them to constantly stick to the personally created schedules in order to achieve their final goal. These programmes are individually adapted to the physical and mental wishes and needs of the athlete. Since it is often a long-term goal, it is aimed at a step-by-step positive development of the athlete's abilities and skills.

The theory of supercompensation (Zatsiorsky & Kraemer, 2006) is at the heart of the realisation of this long-term growth. It approaches physical and mental development over a longer period as optimally as possible, taking into account the needs and demands of the body and the mind.

Theory of supercompensation:
There are four phases in the load-recovery-supercompensation principle:

1. Start: The level of training the athlete is at initial level of preparedness
2. Depletion: The amount of energy consumed in this training
3. Restitution: Recovery after training. This recovery depends on the intensity of the training
4. Supercompensation: The body will adapt itself in such a way that the athlete will reach a higher level

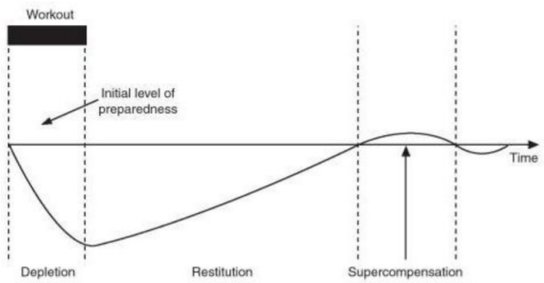


Figure 17. Theory of Supercompensation

There are three scenarios of development over time. Most important is the time between the training impulses and the load. The secret of good training are rest and recovery. It is crucial to take time to 'rest' between impulses to avoid exhaustion. If there is too much or no rest, it can lead to a constant or negative long term effect.

So there is an optimal moment for a stimulus and an optimal moment for rest, in order to find a new physical and psychological homeostasis at a higher level. This will result in an optimal increase overtime. This means that the athlete or the coach sometimes has to put the brakes on in order to take rest and not to overdo it and run the risk of getting injured.
The top athletes stay on track by setting appropriate short-term goals together with their coaches: these goals keep athletes focused on milestones which are tactically chosen on track towards achieving the long-term goal. Bo Hanson (4x Olympian, 3x Olympic Medallist, Specialist Coaching Consultant) states in an article Athlete Tough (n.d.) that that short term goals are the foundation for performing when it is really needed:

- Short-term goals should provide feedback about performance and the road ahead, by being realistic.
- *"A successful short-term process goal, is one which breaks down the critical or match-winning actions and brings our focus back to the field of play where we have control over our own choices and behaviour. It's these choices and behaviour that have a capacity to influence the end result."*
- Coaches and athletes should design meaningful goals together.
- Mental preparation is a skill, which needs to be practised.
- *"It's critical that these short-term process goals are measured and reviewed consistently and become part of the preparation".*

The achievement of goals is not only a matter of individual performance, it is a team effort. Athletes have a whole team of specialists and supporters around them; coaches, trainers, physiotherapists, psychologists, dietician, social environment, etc. These experts motivate, support, steer and guide the athlete. The professional team of experts must be able to identify deficiencies in performance (physical, technical, tactical, etc.). This is done on the basis of various tests that, for example, improve the physical condition, learn or perfect a technical skill, strengthen mental qualities such as performance motivation, favourably influenc health and/or develop a suitable physique (Sport Vlaanderen, 2017). On the basis of the test results, the team builds up, evaluates and adjusts one's training schedule and encourages adherence. These experts support the athlete not only as experts in their field, but also on a personal interaction level. The experts understand the athlete and empathise with them. By providing personalised support based on expertise, data and empathy, the athlete's motivation is boosted and the intended performance is attempted to be achieved.

Supercompensation theory. The vertical axis is both for the amount of substance and for the level) of preparedness. There are three situations with rest intervals between sequential training workouts: (a) The intervals are too short and the level of athlete preparedness decreases due to accumulated fatigue; (b) the intervals are optimal and the ensuring workouts match with the supercompensation phase; and (c) the intervals are too long and there Is no stable training effect.

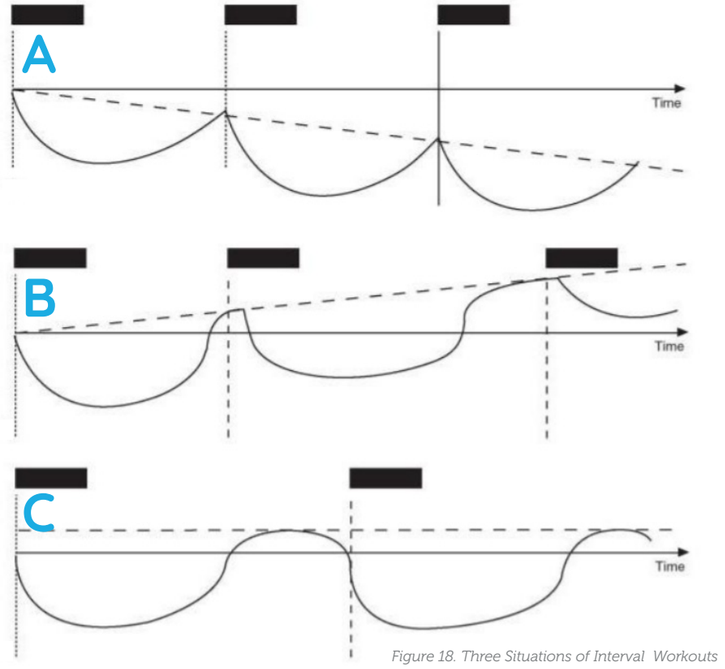


Figure 18. Three Situations of Interval Workouts

Topsport Training Coach as MI Partner-Patient Intervention

As previously described, Condon & McCarthy (2006) show that after an MI, patients try to make several lifestyle changes at once out of fear and a need for control. Nevertheless, this is not the necessary intrinsic motivation to attain long-term lifestyle change and could result in depletive exhaustion of motivation. Therefore, patients often do not maintain this practice. Since athletes are coached at top level and can consistently train and maintain their lifestyle towards a certain goal, it is useful to learn from this field and implement the insights for an MI lifestyle intervention.
Connecting the model by Kwasnicka, Dombrowski, White, & Sniehotta (2016) to the Theory of supercompensation (Zatsiorsky & Kraemer, 2006), a reasoning could be that motivation can be exhausted if too much behavioural suppression has to be applied at once for a longer period. The patient does not take enough rest and the "load" is too much. This can lead to an accumulation of fatigue and depletion of motivation, and thus the abandonment of the goals set to cause changes in lifestyle.

A step-by-step structure could be offered with intermediate goals towards an end goal. Important factors of an intervention would be:

- Controllability of actions
- Realistic goals and performance feedback
- Goal revision instead of failure
- Awareness of individual influence
- Cooperatively setting meaningful goals
- Mental preparedness through practice
- Personalised support by experts and people close to you

Furthermore, it is important to take a rest in-between and to make a slip now and then. This is also indicated by several patients: *"Rehabilitation is two steps forward one step back, and that is not a bad thing"*. To make the steps-by-step life time programme more effective, ups and downs need to be taken in account as a normal phenomenon.

Another insightfull sports metaphor is that the patient's partner could act as a 'personalised support system', if they use their insights into the patient's performance. There is usually no one who knows the patient better than their life partner. So could the partner be 'used' as an expert to support the patient and work towards the lifestyle goals? The partner would be able, in cooperation with health professionals, to provide a safety net, feedback, insights and a motivating environment for the patient.

According to the aforementioned theory (p.21), the patient's partner is able to have a positive effect through support and communication. In an ideal situation, the motivation curve of a patient could be monitored. On the one hand, when the patient's intrinsic motivation is low/dropping, the patient's partner could be stimulated to provide an excitatory motivation impulse as a 'understanding coach'. On the other hand, if it noticed that too little rest is being taken, the partner could intervene by inhibiting, and encouraging the patient to take some rest to keep the change enjoyable. Partners and patients can even set meaningful lifestyle change goals together, which would be not only beneficial for the patient, but also for the partner's health. In addition partners could participate in creating an optimal performance environment for the patient. No matter how they participate, it is important that the goals are actually controllable. That is why it is important that an "expert" thinks along, providing input about the objectives and also supervises and revises the process if needed.

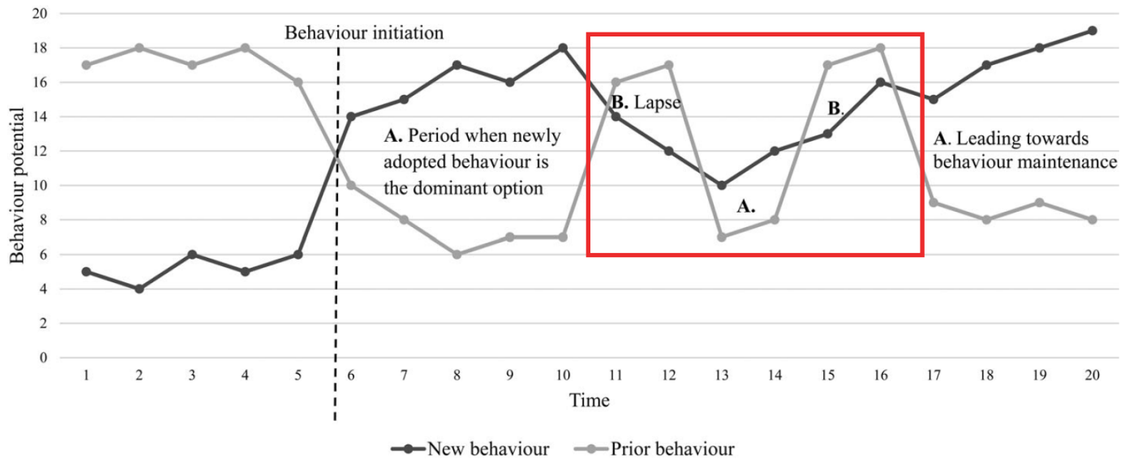


Figure 19. Example Behaviour Change

Supporting Lifestyle Change as Addiction Recovery

The second domain that is studied is addiction recovery. To a certain extent, addiction recovery is also intervening in undesirable behaviour. This involves trying to suppress strong negative behaviour impulses from old behaviour over a longer period of time in order to change lifestyles in the long term. The following models, among others, are used in the addiction intervention care: the Transtheoretical model and Stages of Change and the 12-step Minnesota model. These models are used to make this lifestyle change and to create an intrinsic motivation for the longer term to prevent relapsing and, if it happens, to pick up the process again. These models are examined in the following paragraphs.

12-step Minnesota model

The 12-step model, described by Wilson (2001), consists of affirmations and guiding principles that are repeated frequently by the participants of addiction counselling. The goal is to give back control to the person with the addiction. They are "*reprogrammed*" positively and learn that they can overcome the addiction independently and with the support of the others (Cleanverslavingszorg, 2021).
The focus of the program is to learn what pitfalls and triggers are and what choices are best for ones health. To prevent relapse, a relapse prevention plan is used: this is a personal plan where clients write down their triggers: people, objects, things that remind them to usages and the consequence of usages. The plan is a guide which provides grip to control the addiction (Recovery Expert, 2021). This allows a client to identify their own triggers so that they can intervene and thereby prevent a relapse. This requires continuous awareness on the part of the client.

The program is supervised by recovery coaches. The coaches, who are not medical clinicians, could create a more trusting and non-judgmental dynamic between them and a client (Recovery Expert, 2021). They serve as an advocate for their client and are *"on their side"*.
A coach offers the following tools and guidance to people that try to overcome their addiction, which are displayed in the table on the left.
Recovery coaches can also involve friends and family if needed (Familiesagainstnarcotics, 2021). They work on creating a safe environment for the client through:

- Walking friends and family through the steps of the recovery process
- Evaluating and talking about the goals of the client
- Determining both long- and short-term treatment plans.
- Providing support and guidance to families who have a loved one struggling
- Developing strategies to create positive change throughout the family dynamic
- Assisting to create a calm, non-judgmental environment
- Helping family members establish healthy boundaries
- Guiding them to additional community resources

Coaching Tools and Guidance (Office of Addiction Services and Supports, 2021)
• Helping a person form a plan of action
• Directing that person to the right resources
• Helping them navigate the medical system
• Providing accountability and support
• Offering guidance in developing new behaviour patterns
• Helping them view their progress objectively
• Assisting in harm reduction for addictive behaviours

Table 6. Coaching Tools and Guidance

Step	Content	Action
1:	Recognise your addiction and the powerlessness.	Recognizing
2:	Admit that you need help.	Acknowledging
3:	Accept the help.	Accepting
4:	Taking stock of your life.	Considering
5:	Confess your misdeeds to yourself and to others.	Admitting
6:	Discover your weaknesses and shortcomings.	Understanding
7:	Work on your shortcomings and weaknesses.	Overcoming
8:	Make a list of people you have harmed and be prepared to make amends.	Reflecting
9:	Actually seek contact with these persons and try to make amends, unless you would hurt them or others by doing so.	Forgiving
10:	Make it a habit to look critically at yourself and immediately recognise the mistakes you make.	Sensing
11:	Create peace in your life through meditation or something that allows you to experience this peace and tranquillity.	Maintaining
12:	Pass on your experiences to others who need it.	Sharing

Table 7. 12-step Minnesota Model

Transtheoretical model and Stages of Change
The transtheoretical model and the stages of change described by Prochaska, Redding, and Evers (2008). This is a model used by addiction therapy coaches that represents the initiation of change in negative health behaviours. According to the circular model, as seen below, five different steps are followed. The model starts by building up motivation until there is enough to actually start performing the healthy behaviour, after which this behaviour is maintained or the person relapses. Ultimately, a constant form of behavioural maintenance is achieved. Prochaska, Redding, and Evers (2008) also provide various strategies on how to switch between the different phases.

Precontemplation Stage: Does not intend to take action in the near term
1. Consciousness raising
   Finding and learning new facts, ideas, and tips that support the healthy behavior change
2. Dramatic relief
   Experiencing the negative emotions (fear, anxiety, worry) that go along with unhealthy behavioral risks
3. Environmental reevaluation
   Realizing the negative impact of the unhealthy behavior or the positive impact of the healthy behavior on one's proximal social and/or physical environment

Contemplation Stage: Balancing costs and benefits
1. Self-reevaluation
   Realizing that the behavior change is an important part of one's identity as a person

Preparation Stage: Intent to take action soon
1. Self-liberation
   Making a firm commitment to change

Action Stage: Overt modifications
1. Helping relationships
   Seeking and using social support for the healthy behavior change
2. Counterconditioning
   Substitution of healthier alternative behaviors and cognitions for the unhealthy behavior
3. Reinforcement management
   Increasing the rewards for the positive behavior change and decreasing the rewards of the unhealthy behavior
4. Stimulus control
   Removing reminders or cues to engage in the unhealthy behavior and adding cues or reminders to engage in the healthy behavior

Maintenance Stage: Prevent relapse

Relapse Stage: Learning from relapse

The model shows that successfully taking steps towards overcoming addiction is supported by guiding clients as best as possible to go through these phases in the right way, building motivation gradually (Prochaska, Redding, & Evers, 2008). The different strategies provided by the model can be used to guide clients from one stage to the next. Understanding the motivation of clients is a critical aspect for coaching. This includes the different types of motivational drivers and inhibitors, and what is needed to maintain this on a longer term.

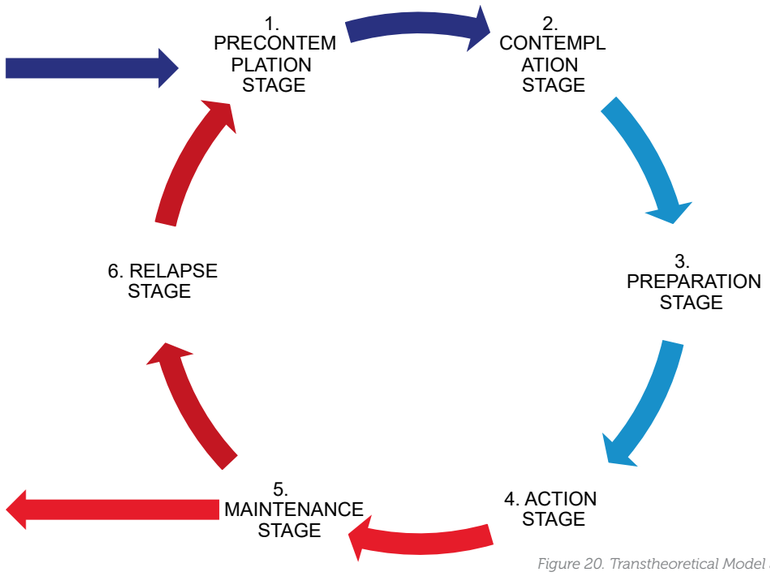


Figure 20. Transtheoretical Model and Stages of Change

Addiction Recovery Coach as MI Partner-Patient Intervention

Translating the models of addiction recovery to the MI patient and partner, interesting elements for an intervention for stimulating long-term lifestyle change emerge. Three identified key insights are: motivation guidance, lifestyle change is a learning process and empowering families to support.

Motivation guidance
The transtheoretical model and the stages of change clearly show that motivation is a path that needs to be built up. Currently, for MI patients, this motivation path is not layered enough, resulting in a motivation peak and radical change. As a result, the basis for motivation is not strong enough for the long term. By following the steps of the model, it can result in a better foundation. The steps could be used as ways to stimulate motivation within dyadic relationship.
The following is an example of how a step of the model can be used: Weinman, Petrie, Sharpe, & Walker (2000, p.10) argue that *"it would be valuable to elicit the causal beliefs of patients and spouses soon after the MI in order to identify those patients who would be unlikely to engage in the recommended changes in health behaviour and to provide interventions to modify causal attributions as a basis for facilitating recovery"*. The elicitation of causal beliefs could be used to identify those couples who are 'stuck' in the (pre) contemplation phase and need extra help in acknowledging their control over the course of the illness. This would enable couples to responses appropriate to the situation.

Lifestyle change is a learning process
The second insight is that lifestyle is a constant learning process. People who learn to overcome their addiction are constantly aware of triggers and actively write them down. In this way they know what causes them to exhibit the "unhealthy" behaviour. In this way, they consciously build in the 'handbrake' to avoid giving in to temptation, which makes it easier over time. This could also be applied to patients and partners. If they are educated, gain insight and are supported in recognising triggers and temptations that cause them to give in to a craving or lose motivation, they can act in a conscious manner. In addition, they can work together to remove triggers within the living context and lifestyle. Should a situation arise where a patient relapses into his old behaviour, it is important that the patient learns from the experience. This will prevent similar future situations from happening again.

Empowering families to support
The third insight is that the role of a family coach is to guide families so that they know what they can expect from the recovery process. In doing so, they are trained and guided in how to best accompany the client. This is also a need of the patient's partner. Currently, little or no attention is paid to how the partner should engage with and support the adjustment process. This leads to tension and dilemma's within the relationship (Goldsmith et al., 2006). Therefore, it is important to have professional guidance on how the social context can meet the expectation of participation from the care system and the needs of the patient. This allows the social context (e.g. the partner) to keep an eye on the behaviour and progress, if they know what to look for. In addition, they learn how to they can participate to do as much as possible in creating a health stimulating, non-judgemental environment. More involvement of the social context could result in more insight into the lifestyle behind the front door for healthcare professionals and that the alert is raised earlier in the case of possible problems.

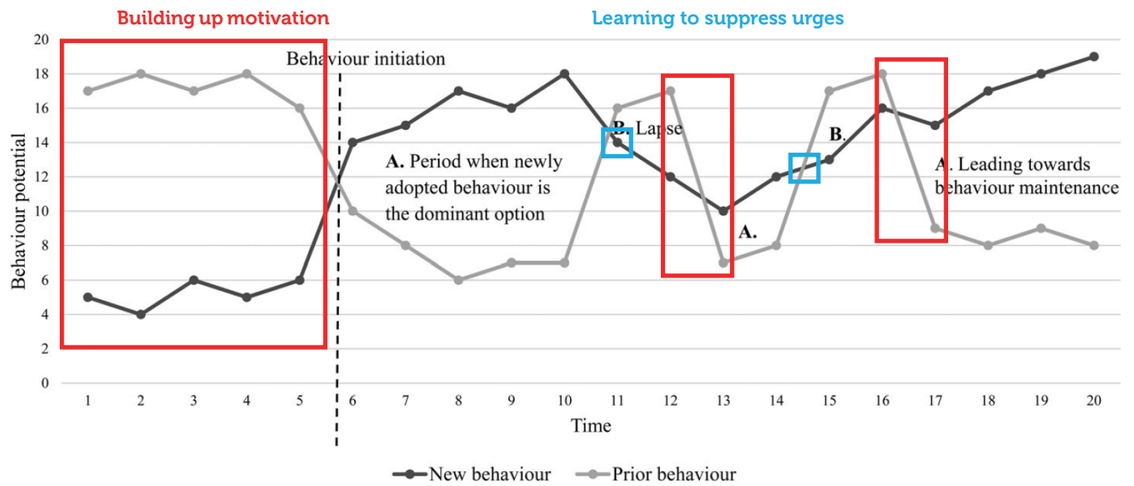


Figure 21. Example Behaviour Change

3.2 Technology

As a means to a solution

Now that the solution space is broadened by reframing the support, the possibilities of realising these solutions through a blended eHealth intervention are being explored. Recent developments in the use of SMART and communication technology have made it possible for LUMC to monitor and support patients from a distance (Treskes et al., 2017). This technology contributes to the improvement of behaviour and motivation related to lifestyle change adherence (Michaud, Ern, Scoggins, & Su, 2021). In this section, the current status and the future of telemonitoring are researched by looking into current technology and related trends.
First, the current technology used by the LUMC Hart Long Centrum to monitor patients at a distance, The Box, will be examined. Secondly, technological developments in the field of monitoring and how this might benefit the current box and the involvement of the social context are considered. This will provide an insight into what is feasible in the future in terms of eHealth intervention technology.

Current tech

In the current situation, MI patients are given a box of wearables with SMART technology (sensors) to take home (Treskes et al., 2017). With these various wearables, they have to perform health data measurements themselves. The patient uses an application for their smartphone, the LUMC Care App, to share the medical data with the care professionals. The care professionals then analyse whether any abnormal data is found and whether to intervene. Ultimately, the patient is presented with an overview of their data and the healthcare professional can view the data in the patient's medical record. In this technological innovation, three functions are central: Sensing, Analysing and Feedback. These functions are described in more detail below:

Sensing

Wearable technology is currently used for the sensing function allowing healthcare professionals to monitor patients outside the hospital (Dunn, Runge, & Snyder, 2018). The wearables in The Box are used to collect medical data from the patients. What sensors are in The Box varies by patient group. For patients with MI, it contains at least a blood pressure monitor, a scale, a pedometer and a device to make an electrocardiogram (ECG) (Treskes et al., 2017). But with the addition of different boxes in different disease areas and places within the hospital, there is a whole range of boxes and sensors available (see images).

The patient is asked to make the measurements (collecting the data) about three times a week. These measurements can be done easily and quickly within five minutes (van Winden, 2020). The patient is expected to use the app on their own initiative. There are currently no reminders or notifications to perform a measurement. After collecting the data, it will be analysed by the software.

Analysing

Little analysis is carried out on the data of the current box service. The data is collected, and is sent directly to the patient's application and the Medical Patient Record (MPR) where healthcare professionals can access the data. Based on the data a timeline of data points is created. But apart from that, there is little automatic interpretation/analysis.

The Hart Long Centrum is, however, working on software that uses Artificial Intelligence to process the data (van Winden, 2020). The aim is to develop a system that gives a warning when abnormal values are below or above a threshold value. An automated algorithm will search for predefined irregularities in the data and assess whether or not it is necessary to act on the warning (Treskes et al., 2017).

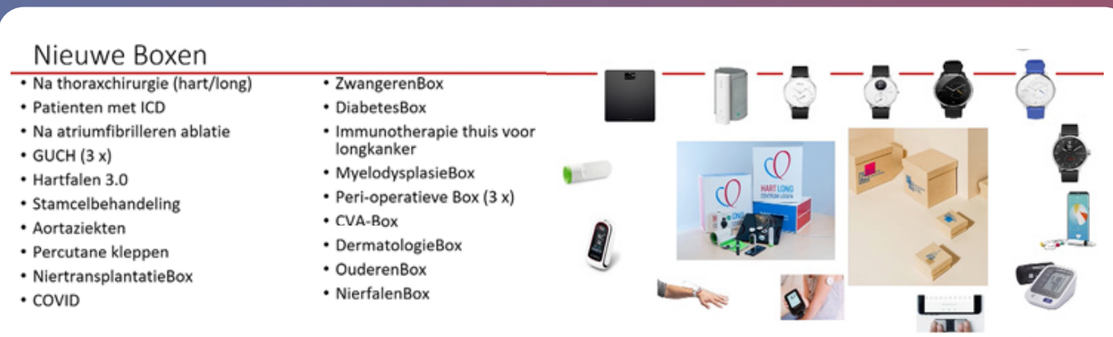


Figure 22. The Box

Figure 23. Sensing - The Box

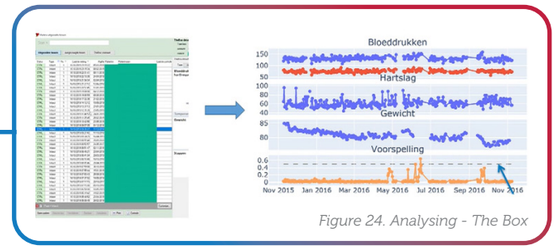


Figure 24. Analysing - The Box

Feedback

Currently, the aim of the box is to facilitate the conversation between the healthcare provider and the patient, so that the support does not stop as soon as the patient leaves the hospital. The feedback system is also designed for this purpose. Yet, the current feedback service is mainly aimed at the healthcare professional and not at the patient. There is still room to improve the service when it comes to empowering and involving the patient. For example, when a patient performs the measurement, they receive only a message that the measurement was successful. The measured data points can then be viewed in the overview, but there is no other interpretation or explanation of what the data means for the patient. Moreover, not all data points are understandable and can be interpreted by the patient; for example, the ECG scan. The current service thus offers room and opportunity for more patient-friendliness and involvement.

The Hart Long Centrum is currently in the process of orienting functionalities towards 'chat bot' coach. The goal of the digital coach/bot is to guide the patient through the rehabilitation process. This is done with Natural Language Processing (NLP). An NLP based chatbot an Artificial Intelligence algorithm that communicates with a patient via textual/auditory/visual methods. This would be the first steps towards a coach who supports in the rehabilitation process and with the lifestyle changes.

The healthcare professionals have their own interface for feedback in the medical patient record. Currently, only data points and trends per patient and sensor are displayed. The data is checked by a healthcare professional who contacts the patient when irregularities in the data are seen. The decision-making is currently done by the professional themselves and is not much supported by technology. If irregularities are identified, an appointment can be made or a video consultation scheduled. In the future of this process, the Hart Long Centrum is striving for automation, resulting in user-friendly personal data overviews that highlight important conclusions and data.

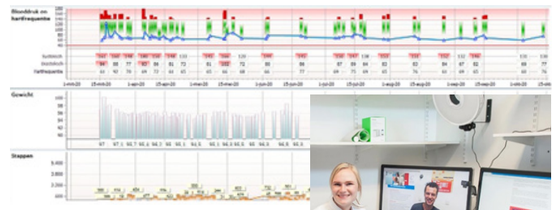


Figure 25. Feedback Care Professional

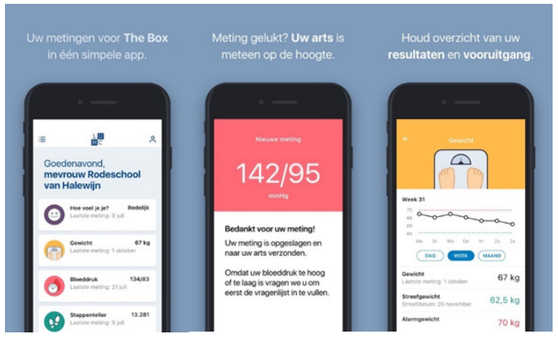


Figure 26. Feedback Patient

All in all, the current box technology is a good basis for the implementation of eHealth in the healthcare system. However, the feedback and integration of the patient and the social context (such as the partner) can still be improved. With today's technologies and data analysis techniques, much more can be done with the translation of this data into insights and actions that can be used and result in patient and partner engagement. The current system mainly serves as an additional flow of information to facilitate the conversation between nurse and patient, but does not yet involve the patient very much in their care. Small clever cues like notifications, alarms, a calendar/schedule, personal interaction, asking for input, explanation of context and data could already be implemented very easily, creating more interaction and satisfying the target group's needs. These improved feedback loops could increase engagement and compliance. This platform offers scope for additional functionalities that can truly involve and empower the patient and context.

Future Tech

As mentioned before, the health system is shifting towards a holistic continuum of care. According to Flores, Glusman, Brogaard, Price, & Hood (2013), the core pillars of this novel perspective are the 'system biology principles': being *'predictive, preventive, personalized and participatory'* (P4). Telemedicine and eHealth are creating new opportunities as a technological bridge between the P4 principles (Alonso, de la Torre Díez, & Zapiraín, 2019). To map the future possibilities of The Box in relation to the P4 and the partner, the futures of the eHealth functions 'Sensing, Analysing and Feedback' are explored.

Sensing: Interconnected Data Streams

The Internet of Things (IoT) is an emerging paradigm that opens up new possibilities through connectivity and participation. Within the field of cardiology, this connectivity is established between human and machine by active use of wearable technology (Pevnick, Birkeland, Zimmer, Elad, & Kedan, 2018). The current Box focuses mainly on the physical aspect, but in the future there is room for expansion to, for instance, the mental and behavioural aspect: Garcia-Ceja et al. (2018) argue that there are measurable interconnections between physiology, behaviour and mood that have the potential to continuously map the mental status of patients and the context in an unobtrusive way.

Over the past few years, these sensor technologies have flourished and as technologies is becoming cheaper and more advanced in the future, they will be implemented more in the medical context. As a result, healthcare providers gain a complete holistic view of the patient and the disease during short and long term monitoring. Cipresso & Immekus (2017) explain that there are two types of relevant sensors that can be used to collect personal data: sensors that monitor the 'internal sphere' - within the body (e.g. biometrics, psychophysiology) and sensors that monitor the 'external sphere' outside the body (e.g. exibited behaviour, (non)verbal communication, environmental data). The Integration of different data measurements could enhance the recognition of specific patterns and relationships. The following figure illustrates what all the possible sensors could measure.

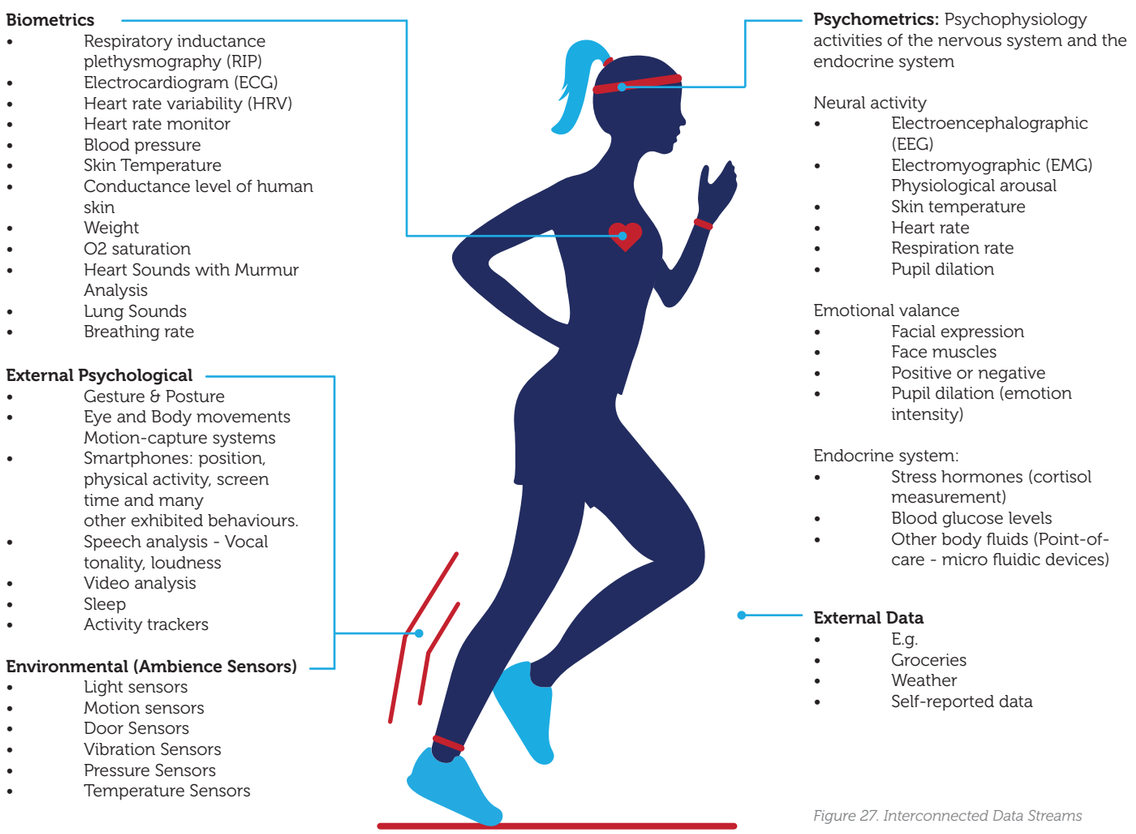


Figure 27. Interconnected Data Streams

Continuous, real-time monitoring of the different data streams (external and internal), can create a personalised image of the patient and their context. In addition, data can be collected at various levels in the patient's ecosystem. Pevnick et al. (2018) provides an overview of the interrelatedness of data sources within the human ecosystem. These are different levels in which data can be collected regarding the patient to gain insight assessing the bidirectional interplay of systems. By combining different data streams from, for example, different patients with the same condition, new insights can be gained, such as interactions within different relationships and triggers for negative health behaviour. In the present, many sensors for monitoring behaviour and mental status are only used in experimental research, since they are often not user-friendly and expensive. However, as these kind of sensors become cheaper and more sophisticated, it is only a matter of time before they can be used commercially.

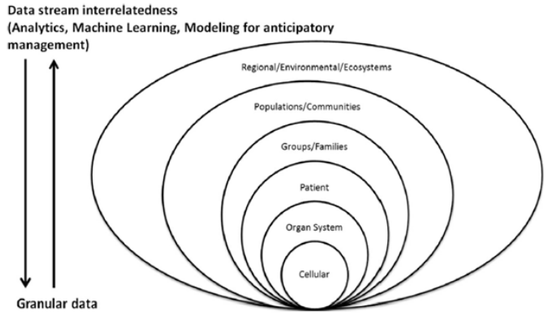


Figure 28. Data Interrelatedness

Analysing: Human-centred AI

Cipresso & Immekus (2017, p5) state that *"the increased computational capacity that is currently available provides a new approach to quantitative psychology, and, more generally for measurements, to think well beyond just the new way to analyze data."* With increased computational capacity, they are referring to artificial intelligence, innovative algorithms and new ways of processing and managing big data. In order to process all these potential data streams, smart algorithms will have to analyse human (behavioural)data and translate it into usable insights in the psychological status of the patient and context.

For the use of technology to quantify psychology, the analysis of the cooperation between humans and machines is of particular importance. This field of technology is called human-centred artificial intelligence (AI). *"Human-centered AI is a perspective on AI and Machine Learning (ML) that algorithms must be designed with awareness that they are part of a larger system consisting of humans"* (Riedl, 2019, p.1). Through smart algorithms driven by AI pattern recognition, human experiences will be able to be quantified. With this data, it would be possible to predict and identify, for example, the patient's status and coping mechanisms over time, the changing needs and attitudes of the patient's social context, and when an intervention is needed to boost long-term adherence. A human-centred AI system should be able to continuously analyse and learn from human language, emotions and behaviour through these smart algorithms. To this end, various biophysical metrics can be used to obtain a picture of the psychological status of patients (Cipresso & Immekus, 2017).

Feedback: Hybrid Intelligence

The most promising future key technology that could drive the functionality 'feedback' is Hybrid Intelligence:

"We define hybrid intelligence (HI) as the combination of human and machine intelligence, augmenting human intellect and capabilities instead of replacing them and achieving goals that were unreachable by either humans or machines." – Akata et al. (2020, p.19)

Hybrid Intelligence (HI) requires a profound subtle understanding in the relationship between artificial intelligent agents and humans. The Hybrid Intelligence Centre (2021) state that this meaning full interaction consists of discussing, aligning, clarifying intentions and performing actions. The improvement of human-machine capabilities can be achieved in a few ways. Akata et al. (2020) describe four approaches how humans and machines can interact and enhance each other, resulting in

- Collaboration

Synergy between machine and human - the machine should communicate in different ways with the human and should understand the (social) behaviour of the human.

- Adaptation

Dealing with the dynamic environment – changing along to for example changes in the environment or in the needs and preferences of the user.

- Responsibility

Trust, authority and transparency - using shared values of the system to guide decision making to avoid negative consequences.

- Explainability

Understandability and usability - interpreting and explaining the predictions of complex models to users and explaining complex human behaviour to the models

The purpose and goal of the HI is to strengthen *"human capacity for learning, reasoning, decision making and problem solving"* (The Hybrid Intelligence Centre, 2021). Therefore, this technology offers the ideal opportunity to guide the patient and the partner in the adaptation process and lifestyle change and to support the healthcare professional in providing the appropriate care plan.

These insights can be used in the 'The Future Box' as guidelines for the interaction between the technology and the various

relevant stakeholders. The AI system would bridge the needs and the different languages of the various stakeholders and systems, as a gatekeeper that translates input data from the one stakeholder to understandable output data for the other stakeholder facilitating optimal and meaningful interactions. One example is the translation of biometric data collected by sensors. This data must be communicated to the healthcare professional so that they can check whether the treatment is still appropriate, and the data must be communicated to the patient so that they can gain insight into their own health situation and be activated to continue therapy. In addition, the system needs a certain amount of flexibility to change with the various changing needs of the different stakeholders and continue to steer towards the common goal of the 'Healthy adaptation and self-management of the patient and social context'.

3.3 Future Vision

The insights gained from reframing 'the stimulation of the intrinsic motivation of the patient for long-term lifestyle change adherence by the partner of a patient' and 'the prospect of future technological developments regarding the Box' are plotted within the framework of the P4 (preventive, predictive, personalised and participation). This P4 framework is the core of the a holistic continuum of care and will be used to define the partner's role in it. Based on these clusters, the mechanisms are determined of a meaningful solutions for answering the question: *'How can a partner be guided to stimulate a patient's intrinsic motivation to commit to long-term lifestyle changes and have a balanced relationship'*

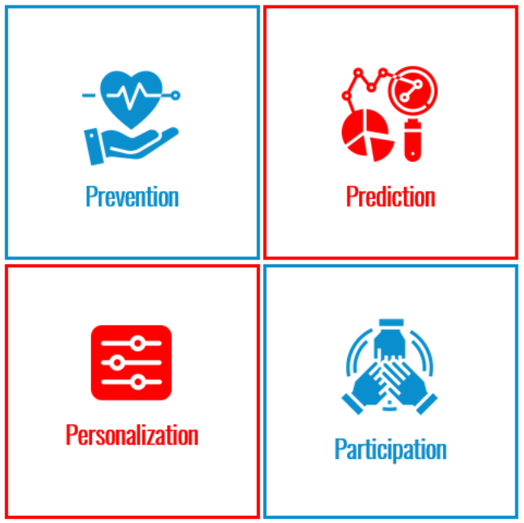


Figure 29. P4 Framework

The above P4 framework has been used to cluster the mechanisms of "how" the partner can be involved in supporting the patient and maintain the balanced relationship. The following outcomes resulted of the integration of the findings:

The partner can prevent through:
- Monitoring (un)conscious performance and behaviour
- Self-education to gain understanding of the process
- Identifying and anticipating triggers to prevent relapse
- Guiding long-term growth through dosing of adjustment

The partner can predict through:
- Mental preparedness – predicting performance barriers
- Performance feedback on status towards long-term goal
- Evaluation and revising goals
- Anticipating on temptations

The partner can personalize through:
- Support based on empathy and expertise (understanding needs)
- Personal coaching: creating meaningful goals together
- Focus on what is possible at that moment in time: skills and abilities
- Take in account the occasional slips and motivational cheating

The partner can participate through:
- Focus on establishing healthy boundaries
- Create a calm and non-judgemental environment
- Think of it as a team effort -shared responsibility
- Be aware of controllability and influence

The above described P4 mechanisms can be used to guide and empowere partners by means of an eHealth box intervention to optimally assist the patient in the adaptation process and fascillitate a holistic continuum of care. The need to play an active and effective role at every moment through the care process can thereby be fulfilled and balance the relationship.
As a direction for the solution, a future is envisioned where the patient's partner is given a central role, participating in changing the lifestyle in the long term through the eHealth intervention. Within this future, the partner will be supported in using the 4P's as tools to support the patient:

Partners will be empowered and guided by the healthcare system, by means of an eHealth intervention driven by Hybrid Intelligence and P4 mechanisms, to positively support the patient in the right way at the right moment in changing their lifestyle in the long term.

4. Design

Based on this vision of the future, a design for a Product Service System (PSS) will be designed in this chapter. The PSS will help partners to express their willingness to support the patient in a positive, effective and balanced way. By doing so, the system is able to realise the common goal of all stakeholders: "Healthy adaptation and self-management of the patient and the social context".

4.1 Design Goal

Improvement Opportunities

In the previous chapters the following key improvement opportunities were identified:

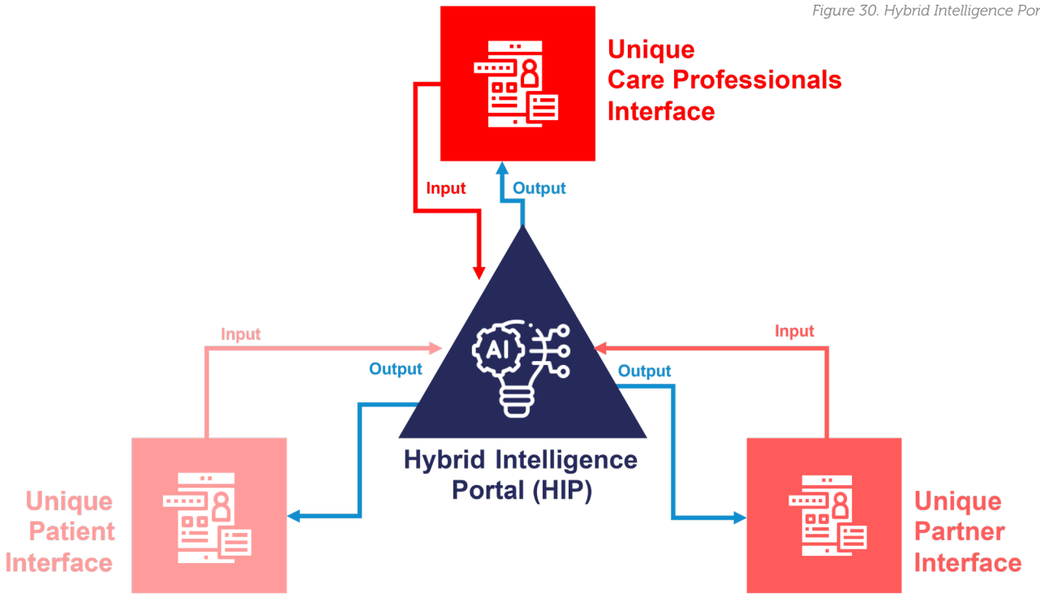
(1) The current Box innovation is currently mainly focused on the perspective of the healthcare professional. Improvements can already be made in the functionality of feedback without the need for complicated technology to integrate the patient/partner and steer towards empowerment based on the collected data.

(2) Partners of patients are hardly involved in the care process while they play a key role in adaptation and lifestyle change. Yet they have the ability to positively influence the behaviour and attitude of patient using the P4 mechanisms leading to healthy behaviour by supporting the patient in the *right way* at the *right moment*.

(3) An HI Agent requires profound subtle understanding of the meaningful interaction between the stakeholders. This allows the system to monitor and translate human experiences and behaviour, aiming for Hybrid Intelligence where collaboration, adaptation, accountability and explainability ensure that the insights can be used for different purposes and meet different stakeholder needs.

It is important to understand that all three stakeholders: patient, partner and healthcare professional, speak a different language, have different needs, but share a common goal: Healthy adaptation and self-management of the patient and social context. To realize this common goal, a PSS is designed which is a portal driven by concept of hybrid intelligence between the patient, partner and healthcare professional.

Figure 30. Hybrid Intelligence Portal (HIP)



The core of the hybrid intelligence concept is that all three stakeholder groups are in their own way 'complex data sources' whereby the platform analyses the complex data and translates it into actionable insights and communicates these back in different ways to different stakeholders in order to meet their unique needs. The core function is that the system manages that the individual needs are met in a way that the joint system achieves the shared vision.

Within this research, the design goal is to provide a service for partner's of MI patients. Through this Hybrid Intelligence Portal (HIP), the most significant problem of the partner is addressed: taking on a balanced role in relation to the life partner (the patient) in the adjustment process to chronic illness. The portal should empower and guide partners in '*how*' to support the patient in the lifestyle adaptation and rehabilitation process in '*right way*' at the '*right moment*'.

Hybrid Intelligence Portal (HIP)

There are two important elements in the design goal that still need some depth before a successful service can be designed:

- What is the right way?
- What is the right time?

These elements are defined using the P4 insights, the needs of the partner and the technological functionalities of The Box.

How can the Partner be Guided to Support in the Right Way?

Coping Education

The moment the patient has had a first infarction, patient and partner find themselves in a situation where their lives change from one day to the next. From a normal life to living with a chronic illness. The care system currently expects the partner to deal with the situation as it is without proper education and guidance. Out of love and worries, the partner often wants to care for the patient and participate as best as possible, but often does not know how to do this properly. Therefore, healthcare professionals should educate the patient's partner with a personalised curriculum and guide them in how to cope with adapting to the chronic illness and stimulate long term lifestyle change.

Balanced Support

The partner thinks more about the long-term impact, and the patient is more inclined to continue living 'as normal as possible'. So the question is how can a partner help in adapting lifestyle behaviour without becoming 'the nagging' or 'non-participating' partner? Important here is the balance between being the 'love partner' and 'coach of the patient'. The aim is to achieve a balance between personal interrelationships and the disease. The partner has the opportunity to look at the patient more objectively and to positively guide their (un)conscious behaviour in the process towards a certain goal. The partner's gut feeling can be an important tool here, as they often already recognise patterns in behaviour that are much more complex to 'understand' by a technological system.

Empathic Communication

Empathic communication is key is encouraging the patient with the pursuit of a long-term goal. If the partner communicates (argues, confronts, talks, acts) positively on the basis of partner knowledge and data (from the care system), and presents this with empathy and understanding, the patient may be more willing to accept it. But to do this correctly, the partner must first be instructed in the best way to do this.

Carey et al. (2018) have compiled a list of Mechanisms of Action (MoA) related to healthy behaviour that can be triggered by certain Behaviour Change Techniques (BCT), see the table below. By using the right technique, the partner's behaviour can be influenced at the right moment. On their turn they can then influence the patient through empathic interaction. Only with the right communication, there can be a balanced healthy relationship between partner and patient in dealing with the chronic illness and adjusting behaviour.

Mechanism of Action (MoA)	Behaviour Change Technique (BCT)
Attitude towards the behavior	Information about health consequences
	Information about social and environmental consequences
	Pros and cons
	Information about emotional consequences
	Framing/reframing
	Salience of consequences
	Material incentive (behavior)
	Incompatible beliefs
Behavioral cueing	Habit formation
	Prompts/cues
	Restructuring the physical environment
	Habit reversal
Behavioral regulation	Self-monitoring of behavior
	Action planning
	Goal setting (behavior)
	Habit reversal
	Behavior substitution
	Discrepancy between current behavior and goal
	Self-monitoring of outcomes of behavior
	Habit formation
Beliefs about capabilities	Graded tasks
	Verbal persuasion about capability
	Focus on past success
	Demonstration of the behavior
	Problem solving
	Behavioral practice/rehearsal
	Reduce negative emotions

Beliefs about consequences	Information about health consequences
	Information about social and environmental consequences
	Pros and cons
	Information about emotional consequences
	Comparative imagining of future outcomes
Environmental context and resources	Adding objects to the environment
	Restructuring the social environment
	Problem solving
	Social support (practical)
Emotion	Prompts & cues
	Anticipated regret
Feedback processes	Information about emotional consequences
	Pros and cons
General attitudes/beliefs	Feedback on outcomes of behavior
	Credible source
Goals	Discrepancy between current behavior and goal
	Behavioral contract
	Goal setting (outcome)
	Review outcome goals
Intention	Information about health consequences
	Information about others' approval
Knowledge	Information about health consequences
	Information about social and environmental consequences
	Instruction on how to perform the behavior
	Feedback on behavior
Memory, attention, and decision processes	Prompts/cues
	Habit reversal
Motivation	Mental rehearsal of successful performance
	Pros and cons
	Identity associated with changed behavior
	Self-incentive
Perceived susceptibility/vulnerability	Information about health consequences
Needs	Monitoring of behavior by others without feedback
	Avoidance/reducing exposure to cues for the behavior
Reinforcement	Nonspecific reward
	Social reward
	Associative learning
Self-image	Framing/reframing
	Identification of self as role model
Skills	Behavioral practice/rehearsal
	Demonstration of the behavior
	Instruction on how to perform the behavior
	Problem solving
	Generalization of target behavior
Social influences	Social support (unspecified)
	Restructuring the social environment
	Social support (practical)
	Monitoring of behavior by others without feedback
	Social comparison
Subjective norms	Feedback on behavior
	Social comparison
	Information about other's approval
	Feedback on outcomes of behavior
Social learning/imitation	Demonstration of the behavior
Social/professional role and identity	Credible source
Values	Social support (unspecified)
	Identity associated with changed behavior
	Mental rehearsal of successful performance
	Commitment

Table 8. Carey et al. (2016) List of MoA & BCT

How can Partners Support at the Right Time?

Situation assessment

Partners can support the patient in various ways, for example, through emotional support or by interfering in risk situations/ relapses. But what is the right moment to intervene? Currently, the patient's partner must do this based on his or her own assessment of situations. At the wrong moments, this can cause a negative influence on the patient and thus on the relationship. At the right time, it can result in positive behaviour and the desired outcome. It is important not to become a 'nanny' of your partner, constantly nagging or snitching on his or her behaviour. But it is also not beneficial to just let everything go. That is why finding the balance in the right moment to intervene is crucial.

Triggering feedback

Patient and partner monitoring not only provides insight for healthcare professionals so that they can adapt the treatment and do a risk assessment, it also allows the partner to gain insight into the patient in order to adjust their social 'treatment'. Through a feedback system, notifications and insights can be shared based on the data being monitored. The feedback may be triggered by certain fluctuations, situations, outliers in the data, moments in time, trends, gut feeling, feelings and emotion. If, for example, an objective is not likely to be achieved or other triggers are activated, feedback is initially sent to the patient. If the patient does not act, the partner is informed that he/she must motivate/ inhibit/influence the patient. If nothing changes, the relevant healthcare professional will be informed so that they can intervene.

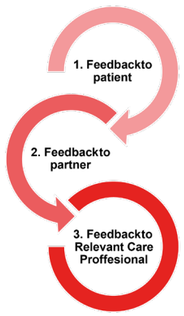


Figure 31. Feedback Levels

Influencing Behaviour Through the HIP:

Based on the previous approaches for empowering and guiding a partner in supporting the patient in the right way at the right time, the following Hybrid Intelligence Portal (HIP) with its associated value exchange between stakeholders was created (figure 32). The proposed portal has 3 main features: (1) Personalized Dyadic Route, (2) Behavioural Support and (3) Lifestyle Education. These features are based on the needs of the partner and the realisation of the common goal of the system. In order to meet these objectives more and more effectively, the technical complexity, data collection and utilisation of the HIP can and will be increased over time.

Feature 1: PERSONALIZED DYADIC ROUTE

The first function is the collective creation of personalised dyadic routes. The first step, for the patient and partner is to add profile information. This information serves as a basis for individual and dyadic assessment. Information to be filled in is biometric information (BMI, exercise, health self-assessment, etc), but also psychosocial (stress, perception of illness, etc). This data is requested several times a year from the partner and patient to monitor progress. In addition, permission asked and given to each other to share and interpret the data. In addition, the patient's partner will also receive a SMART wearable, to use their data as input for the rehabilitation process and improve care for their loved one.

The second step, carried out by the care professional, is making it clear that lifestyle change is a long term journey and determining the major end goal. Under the guidance of a professional, a plan is made together with the partner and the patient to achieve this long term goal. This goal should be an ambitious concrete goal (biometric values and lifestyle targets), resulting in changes that are integrated as habits and routines. The partner and the patient can then view the roadmap via the HIP and together (with suggestions of the portal) determine short term goals and make an action plan on the various dimensions for positive health from Huber (2011):

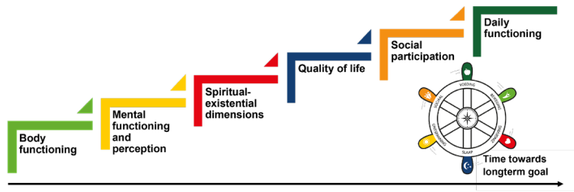


Figure 33. Rotating Lifestyle Goals

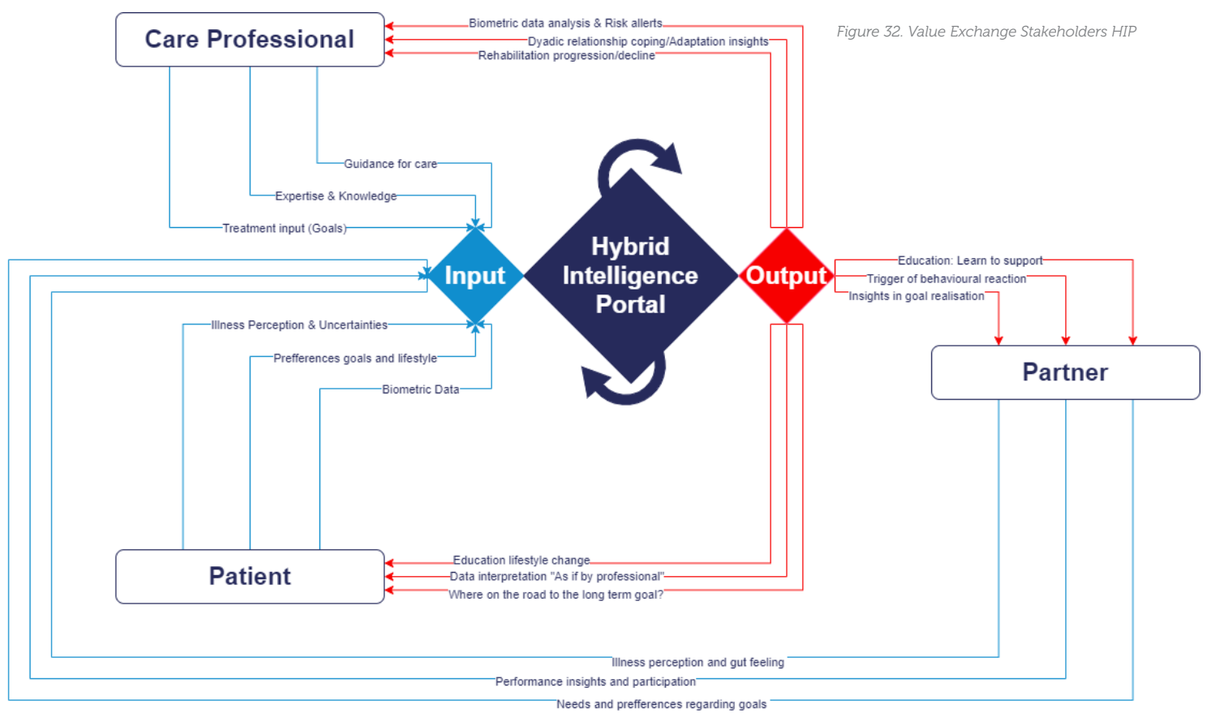


Figure 32. Value Exchange Stakeholders HIP

These points are rotated in the short term so that lifestyle changes can be made together in small steps. Subsequently, it is possible to define what the partner and the patient prefer to focus on. This preference is regularly reviewed through interviews and questionnaires. These rotating short term goals and the connection to the needs of patient and partner are essential to keep the motivation high, maintain the change and achieve the goals. They can also look back at the changes they have already implemented in their lifestyle, obstacles overcome, and what they have already accomplished. The patient's partner will also be offered sensor technology in order to contribute to data collection and insights into lifestyle changes. This allows the dyadic couple to easily monitor progress and rebuild trust together.
The HIP facilitates the regular evaluation of the achievement of objectives (short- and long-term, emotional, motivational). Should it happen that targets are not met due to lack of motivation or other reasons, they can be changed. The effect of this is 'predicted' by the HIP and it also suggests other possibilities (different lifestyle goal, adjust goal, keep going and ask for more support). In addition, the performance of partner and patient is evaluated and assessed by means of Experience Sampling Methods (ESM): *"It consists of asking individuals to provide systematic self-reports at random occasions during the waking hours of a normal week. Sets of these self-reports from a sample of individuals create an archival file of daily experience"* (Larson, 2014, p.1). ESM will be used structurally to give notifications and find out (at the right time, without making people crazy); the coping strategies of the dyadic couple, illness perception and mental status and positive health status. See Appendix B1-3 for example questions that can be asked.

Feature 2: BEHAVIOURAL SUPPORT
The second feature is one to stimulate behavioural support from the partner by means of the HIP, this feature is based on the supercompensation principle (p. 38). The portal uses an AI Agent 'digital medical spokesperson' for communicating directly with the partner and providing the guidance. Based on the insights gained in determining (as a kind of relationship therapist p. 36) how partners can support in the right way and at the right time, a step-by-step process has been created how the system influences partner behaviour and thus ultimately the patient. The 11 steps are visualised and explained below.

Feature 3: LIFESTYLE EDUCATION
The last main feature of the HIP is lifestyle education, backed by the Transtheoretical model and Stages of Change. This feature is provided as if the knowledge and expertise comes from the healthcare professionals. Here the system serves as a rehabilitation coach, who guides and supports the partner through the adaptation process. The most important thing about educating the partner, focussing on self empowerment, creating awareness and knowledge of the importance of changing lifestyle and the role they can play in participating within the process after a MI. It should be clear that lifestyle changes can serve as a tool to get life and their relationship back on track (in balance) after the MI.
Because lifestyle change is a long-term process, it is important that the HIP provides long-term education curriculum at the right time. This can support the partner in the changes by providing answers to the questions: Why is it important, What can I do and How can I do it. The education offered (the curriculum) is based on the relevant personal needs and goals per time frame. For example, in the first phase after the infarct, the focus for the partner is on how to deal with the mental adjustment process. This partner will learn how to regain trust in the patient's body and how to deal with the worries of a recurrent infarction. Over time, however, as the patient's and partner's input into HIP becomes more positive, more confident and ready to look to the future, there will be a shift to, for example, a focus on how to continue living 'normally' while integrating lifestyle changes.

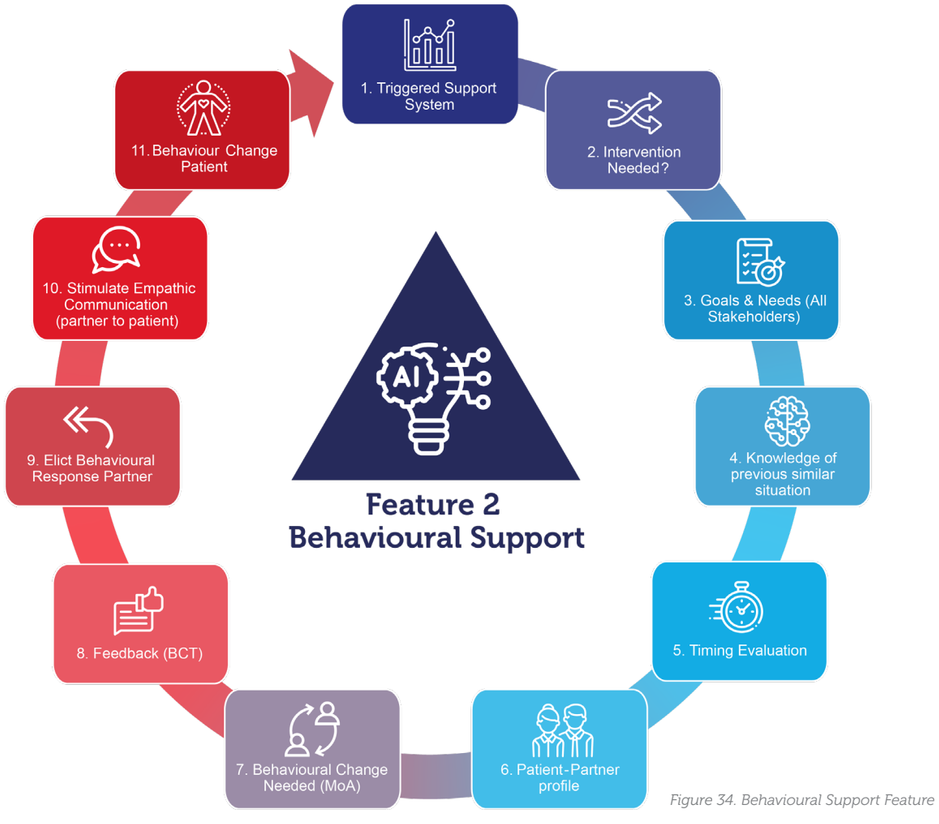


Figure 34. Behavioural Support Feature

1. The support system is triggered by a change or anomaly in the patient's biometric output data patterns; or by trend analysis to identify that a set goal may not be achieved; or a timer alert is triggered, e.g. to long waiting with data measurements.

2. In the first instance, the patient is informed. If the patient ignores the notification or if nothing changes in the data, the system will intervene by means of the partner. (If there is no response to this, then after a while the care professional will be called in).

3. The portal compares the data with the set goals and the individual needs/preferences of all the stakeholders, in order to make suggestions for the best intervention towards the common vision.

4. The portal 'learns' from its experiences (triggers for relapse or decrease of motivation). These experiences are compared to the conditions of previous similar situations. Based on this, the interventions that have worked best for this dyadic couple are identified.

5. As the system receives more data from patient and partner, it gets to know the couple's rhythms and patterns better and better. Based on this information, the timing of a push notification, message and/or email will be determined. The aim is to reach the sweet spot between a specific context/timing and a personalized time based message.

6. Based on the mapped relationship characteristics and self-reported insights of the dyadic couple, the stage of rehabilitation of the couple are identified. The characteristics and insights are used to determine whether the focus is should be on emotional coping and dealing with the past, or whether efforts should be made towards the future (grieving cycle & dyadic experience).

7. The information collected in points 3-6 is combined into a decision on the Mechanism of Action (MoA) of the partner that needs to be influenced in order to support the patient in the right way and at the right time.

8. Based on the MoA and the previous insights, the Behavioural Change Techniques (BCTs) that achieve the desired support are selected.

9. These BCTs are used to elicit positive supportive behaviour from the partner.

10. Ultimately, the partner is stimulated by means of subtle cues to support (stimulate motivation, slow down to prevent exhaustion, etc) the patient in an empathic way through communication or practical help.

11. As a result, the partner is positively encouraged in the short term and remains adherent to changing the lifestyle in the long term. This results in secondary prevention for the patient and primary prevention for the partner through participation and support.

4.2 WeCAIR Features

Illustration of the Hybrid Intelligence Portal (HIP)

To visualise the strategy to influence patient adherence, WeCAIR is designed. WeCAIR is a user-friendly interface designed form the perspective of the patient's partner. As discussed in the chapter before, the interface has three different main features: (1) Personalized Dyadic Route, (2) Behavioural Support and (3) Lifestyle Education. These characteristics are aimed at empowering and guiding the partner to take on a balanced role in relation to their life partner (the patient) in the adjustment process to chronic illness, in order to positively support the patient at the right time in changing their lifestyle in the long term. The different pages with their goals and functionality are described in the following pages.

Figure 35. WeCAIR - Partner Perspective of the HIP

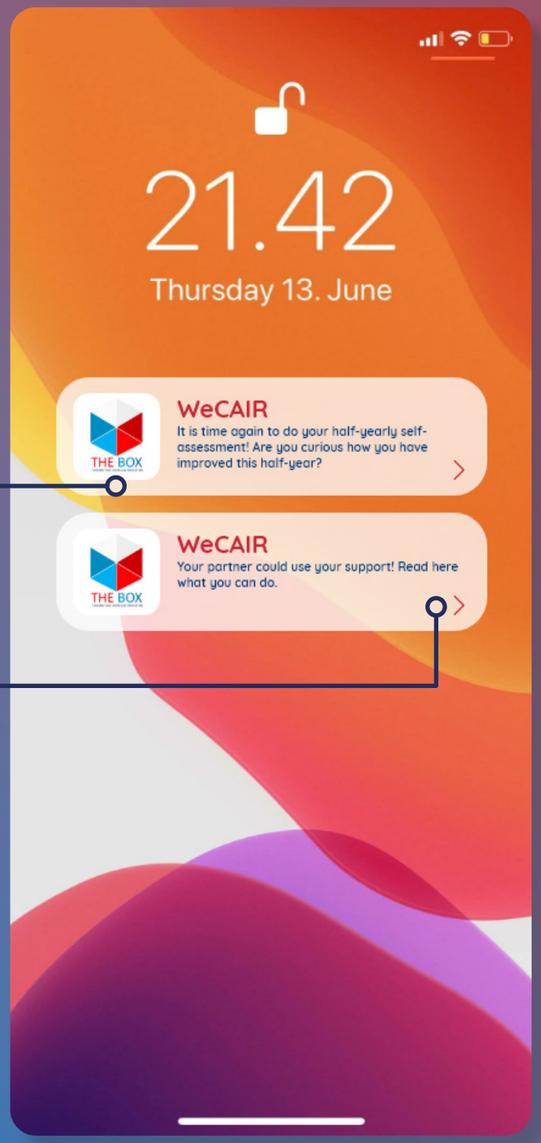
Goal:

Push notifications are an opportunity to interact with partners to notify them that they can give meaningful input in the adaptation process for the patient (using the WeCair app). The notifications appear right in their eye-line as partners pick up their device, making push notifications a powerful tools for driving users back into the app experience and influence their behaviour.

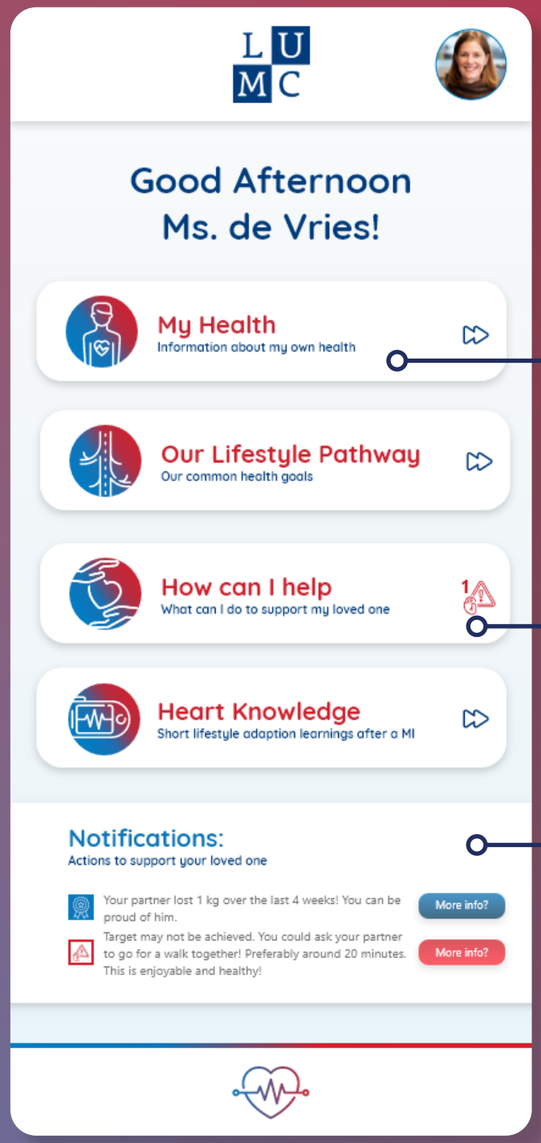
Direct Communication
Feeling of support and being 'helped' by the care professional & Creates awareness that something must be done

To App Guidance
Direct and simple communication nudging one to use WeCAIR

LOCK



HOME



Goal:

Easy navigation is a crucial part of user experience and usability. This is an 'personal' overview of all key features of WeCAIR, where the user is simply directed to the functionality they need at that moment. In addition, 'action cues' nudge them to go to specific pages to see what action is required.

Navigation
Easy navigation through the key needs of the partner which are being satisfied by WeCAIR

Notifications
Signposting and nudging to steer the behaviour of the partner

Goal:

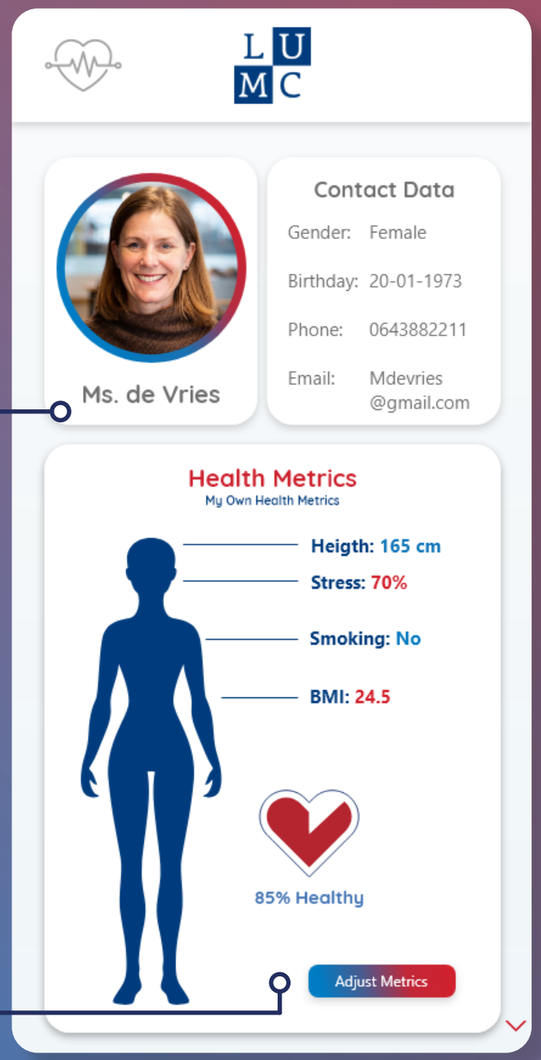
This page presents a personal overview of the patient's partner. The purpose of this page is to create awareness of health and lifestyle. By means of self-assessments (different times of the year) and data measurements, an overview is created of the health status, depression risk/status, illness perception and lifestyle. By doing so, the partner can gain insight into the extent to which the lifestyle is similar to that of the patient and to what extent they themselves are at risk. The aim is to steer towards primary prevention and to stimulate motivation to participate.

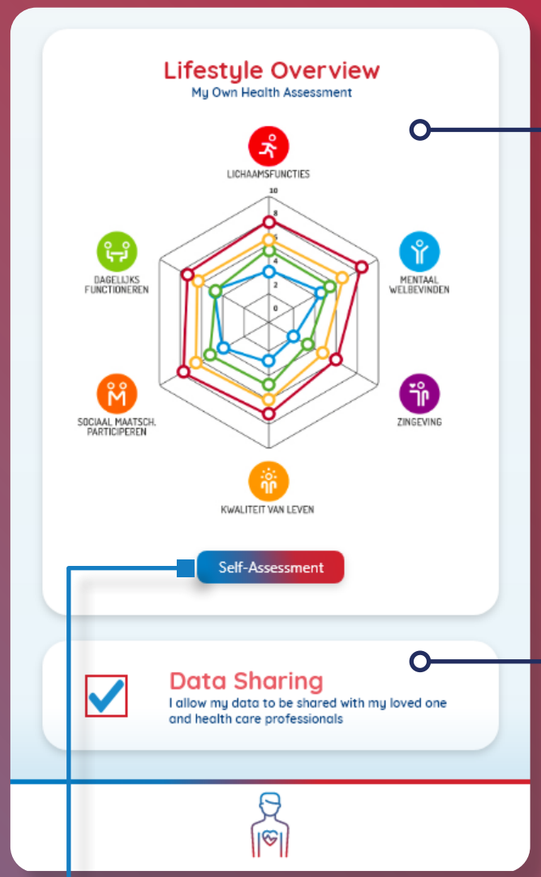
Personal Profile

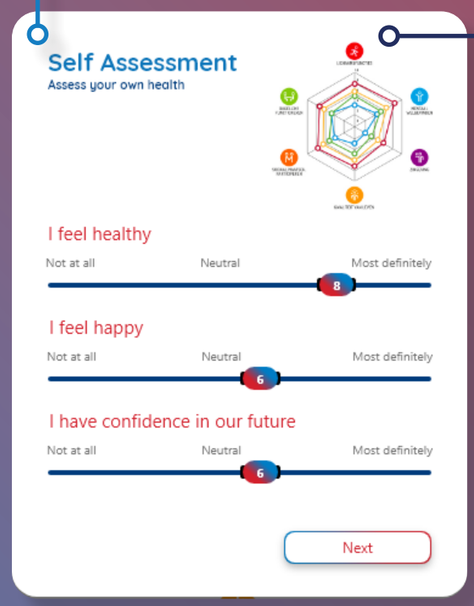
Get an overview of your personal profile , physical and psychological status

Health Status

Get insights in your own health status with your SMART device and become aware of your role in relation to your partner







Participation

Stimulates participation and self-care through personalisation and awareness raising

Data safety

Securely share your data with medical professionals

Self Assessment

Get a good picture of your status through questionnaires and experience sampling

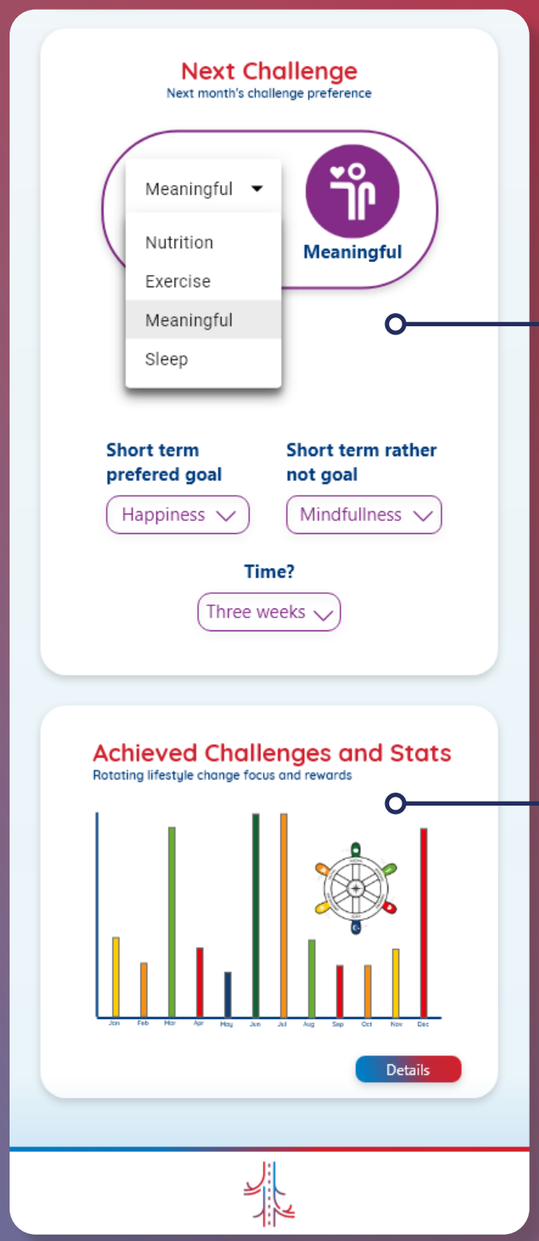
Goal:

The aim of this page is to encourage and maintain a joint lifestyle change by means of a collective journey and shared objectives. The focus rotates across the different lifestyle pillars, based on the needs and preferences of the partner and patient. Together the goals are set, adjusted and evaluated. It is important that this is a year-long plan in which small manageable and fun (motivating) steps are taken together towards the final goal.

Shared Goals
Goals that you and your partner set and work on together

Monitoring Progress
Keep reflecting and adapting the process you are going through

Long Term Goals
Keep an eye on the dot in the horizon and push your limits



Goal Preferences
Decide on the next challenge together! Above all, do what you want!

Accomplishments & Statistics
Look back at the incredible steps you have already made

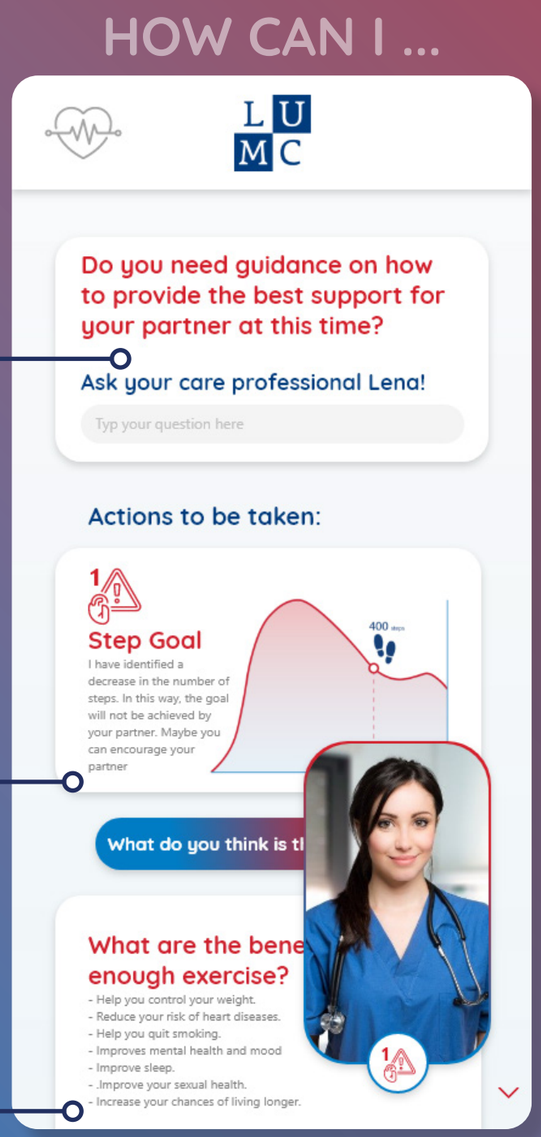
Goal:

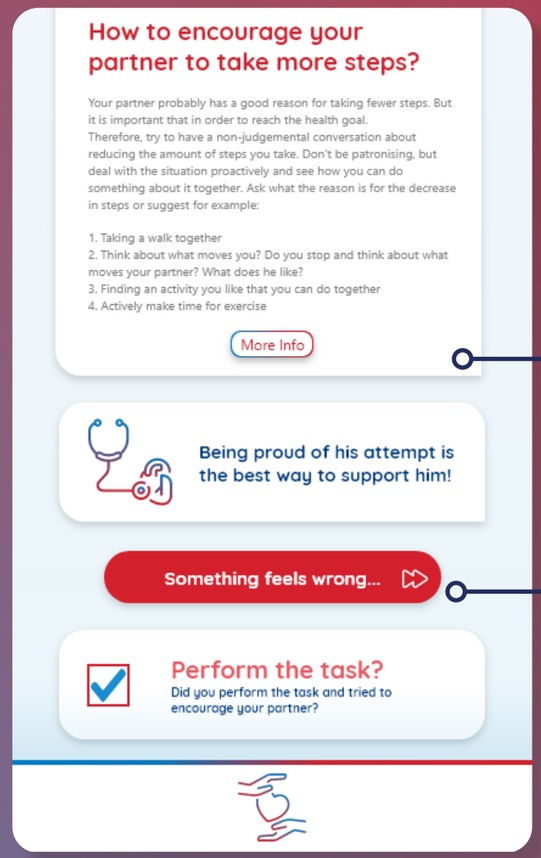
On this page, the partner receives guidance from the 'care professional (agent)', who guides the partner through the adaptation process and offers assistance on how the partner can best support the patient at the right time in the right way, resulting in a balanced relationship. The aim is to make interaction as human and personal as possible. If the patient needs extra motivation or needs to put on the brakes, because he is doing too much and is at risk of exhaustion, the partner will receive an 'action task' from the system. Through this task, the partner will be steered to influence and encourage their loved on in a positive and empathic way.

Professional Interaction
Being listened to by the professional

Personalised Feedback
Understanding your data & provides understanable and actionable feedback

Supporting the right way at the right time
Using Mechanisms of Action and Behaviour Change Techniques to intervene and influence behaviour





Guiding Advice
Guides you in what actions one can take to support

Listens to your gut feeling
Are you worried? Then share your concerns with confidence

Goal:

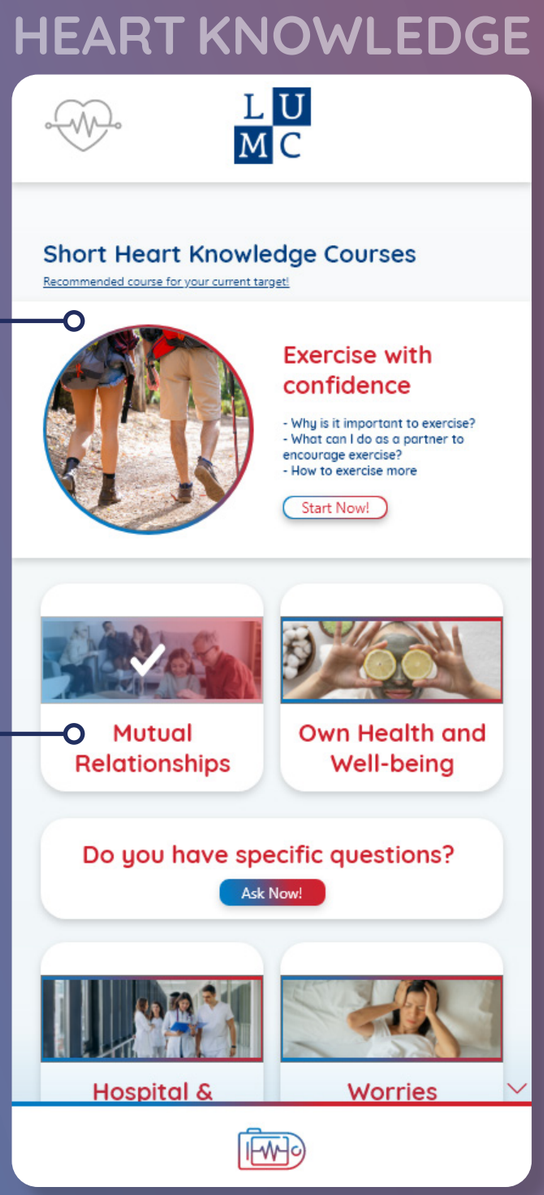
This page offers personalised short courses that are relevant/needed for the partner at that point in time. This depends on the phase within the adaptation process, the illness perception, needs, interest, attitude and lifestyle goals.

Personalised Education

Short courses especially for the partner on living with an MI patient & recommendations based on collected data

Self-Empowerment

Empower yourself by learning as much as possible about the stage and situation you and your partner are in



5. DEEPEN

This chapter takes a more in-depth look at the interactions within the novel proposed Hybrid Intelligence Portal (HIP) system. It will look at the interactions between the stakeholders: Patient, Partner, Healthcare Professional and AI Agent. The aim of this chapter is to identify opportunities for a subtle feedback-interaction system between the stakeholders that increases and maintains intervention engagement and relevance over the long term. Further consideration will be given to how a future eHealth system such as this might be implemented.

5.1 Concept Deepening

Balance Guard

The previous chapter presented the partner interfaces of the designed system. In this chapter we have an in-depth look at the underlying system, the Hybrid Intelligence Portal (HIP). We will examine the different interactions and roles that the HIP as an AI agent will fulfill in relation to the partner, the patient and the healthcare provider. The following question will be central:

How can we refine and humanise the relational interactions between AI Agent, Healthcare Professional, Patient and Partner resulting in a hybrid intelligence system where technology empowers people and people empower technology?

The main role that the HIP system, and therefore the AI agent, will play is to monitor the balance of human dynamic interactions and needs. This translates into several areas; e.g. balance in biometrics and psychosocial data, balance in relationships, balance in lifestyle changes, balance in communication. The following interactions in which the HIP will monitor the balance of the system will be described here: *Consultation Room Experience, Alertness & Risk, Follow-up Diagnosis, Dynamic Nature of Adaptation and an Individual vs. Dyadic Approach.* The diagram on the page opposite shows the different interactions within the system.

Consultation Room Experience

For a true hybrid system, it is important to combine the qualities of technology with those of humans. Within this system, therefore, human pattern recognition (partner) is used in combination with data pattern recognition (AI Agent). The AI agent will function as a Balance Guard that aims for an interaction based on the relation between healthcare professional and partner & patient within the consultation room. The aim is to create a digital environment and communication in which the sharing of experiences, trust and openness are central. The goal is to give the partner a medium where he or she feels heard, can speak openly about the patient's concerns, ask advice, discuss treatment and roles. This interaction is facilitated by the AI Agent in different ways. The partner is approached in a personal way by asking questions about the gut feeling ('pluis – niet pluis'), experience and concerns. By communicating with the partner in this way, the partner feels seen and supported by the care system (see page 34 & 35 for the adaptation process and needs). In addition, the patient's partner is empowered by learning which signs to look out for in order to recognise negative symptoms. This can also counteract overprotectiveness, as the partner knows what to expect and look for.

What is important is that the partner does not become a 'tattletale' to the care system. Therefore, the right balance will have to be found by the system between micro experiences perceived by the partner and the macro process (biometric and psychosocial data over time). To balance this, the role of the partner and the needs of the patient are discussed in the digital consultation room. For example, the patient can indicate how much support they need and prefer from the partner. Based on this, the system will adjust the involvement of the partner in the care. The AI Agent will be leading in decision-making. Only if the AI agent decides that the risks are too great or the quality of care is declining, then the healthcare professional will be called in.

Alertness & Risk

To ensure that the system matches the various human behaviours of dyadic couples on the long term, the HIP will have different alert and risk modes. For example:

1. Pilot light
2. Attentive
3. Warning
4. Alarming

The system can evolve its behaviour from a passive system in the background, with occasional noise, to an active system in the foreground, exerting more pressure and stricter/confronting notifications. This depends on the data collected from partner and patient. If this data is in the range and positive, the system will be passive because the couple is doing well. But if the values deteriorate and the couple becomes more and more negative, the system will become

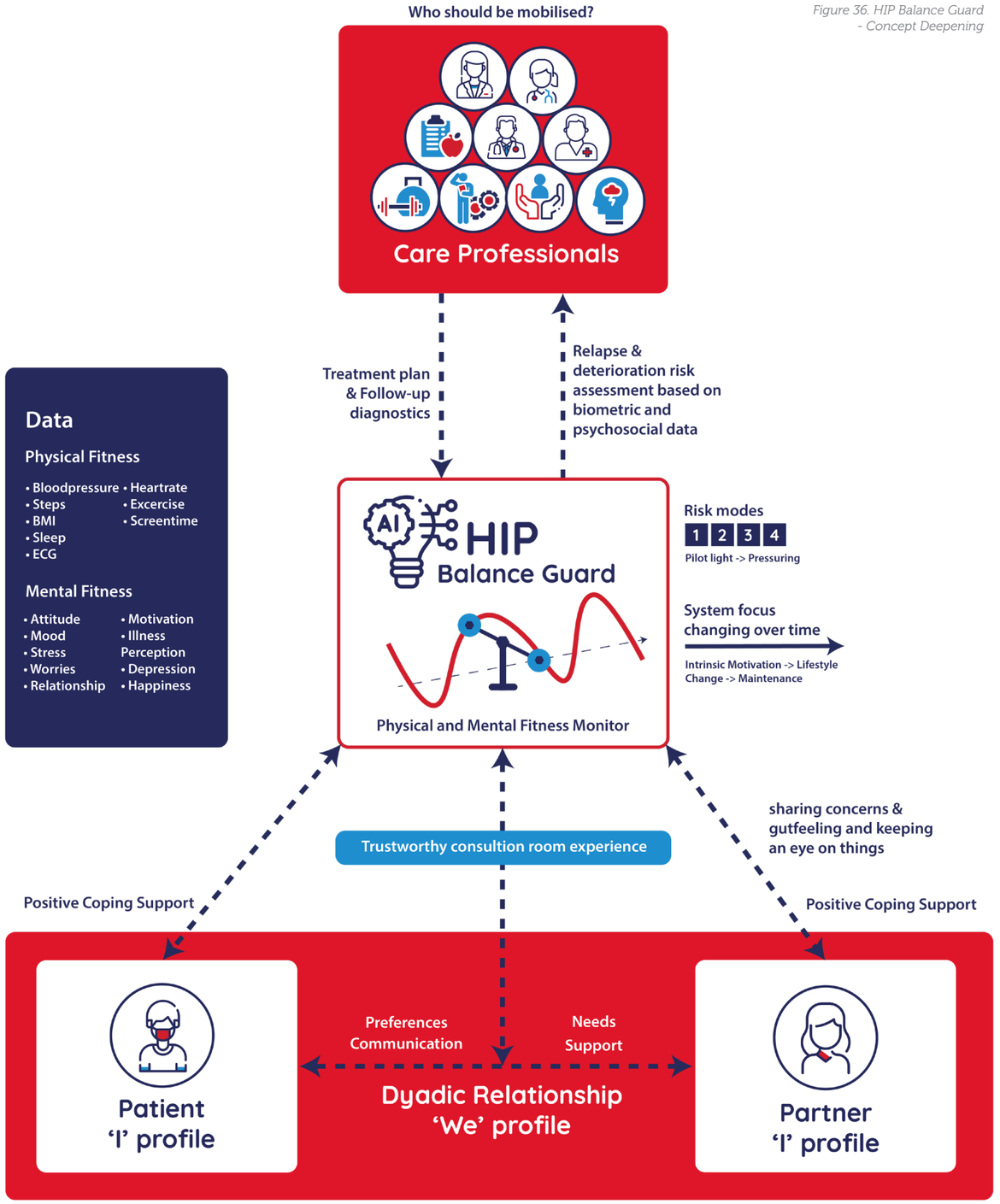


Figure 36. HIP Balance Guard - Concept Deepening

more and more prominent. In ultimate situation, it will call in the relevant healthcare professional. As a result, the system adapts itself based on the data and the behaviour of the couple, with the ultimate long-term goal in mind. It also ensures that couples who behave properly are not constantly bothered with notifications from the system, which also tends to make them use it for longer.

Follow-up Diagnostics

In addition to maintaining the balance for the partner and the patient, the system will also guard the balance for the healthcare professional. This is especially valuable in the follow-up diagnostics of the system. Here, the system will serve as an information gateway that decides which data will and will not be shared with the healthcare professional. The aim is to solve and handle as much as possible within the system. If the risk increases to such an extent, or there is something going on that the system does not understand, help will be called in from a relevant healthcare professional. In the first phase of the rehabilitation process, this will probably be the cardiologist, in the next phase perhaps a dietician or physiotherapist, and in the final phase perhaps the GP, resulting in a long term system.
The gateway consists of various thresholds around the biometric and psychosocial data that is collected. This creates a risk profile that acts as a kind of barometer for the healthcare professional. These risk profiles are drawn up for individual partners and the couple. This provides the care professional and the AI agent with insights into the health, coping and adaptation of the pair. Based on these data and profiles, a personalized treatment plan will be drawn up and executed by the HIP, guiding the couple towards primary and secondary prevention.

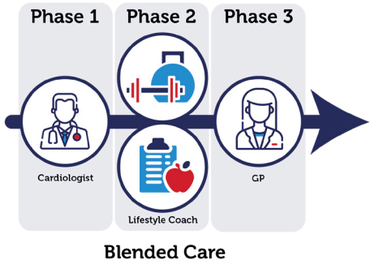


Figure 37. Follow-up Diagnostics

Dynamic Nature of Adaptation

As illustrated by the grieving cycle and the adaptation process (p. 28, 34 & 35), the needs and preferences of both patient and partner change over time after the infarction. In order for the technology to match human needs as closely as possible, it is vital that it adapts to the process in terms of functionalities. To do this properly, it is necessary to have a clear understanding of the couple's situation. In the first instance, the 'baseline' will be determined in collaboration with the care professional and the couple, as well as the end goal. This provides a clear starting point and a clear end point. Subsequently the HIP system will change based on the input and data of the patient and partner. An example route would be:

1. Dealing with the blow, the shock and uncertainty
2. What does the rehabilitation process look like
3. Return to work
4. Looking to the future
5. Adapting one's lifestyle
6. Maintaining lifestyle

The place on the route is determined, among other things, by the answers to the AI Agent's questions, the time that has passed since the infarct, the data collected and the change in needs and preferences.
As previously discussed (p.19 & 20), in the natural process of adaptation, a sense of normalcy is the most important aspiration for patient and partner. The risk of this is that over time the feeling of 'being normal' will take over from the importance of adjusting one's lifestyle. Therefore, it is important that the HIP system balances this 'realism' that someone is still a 'chronic patient' with being a 'healthy human being' over time by reminding the 'patient' in an appropriate way (based on the risk mode).

Shared and individual lifestyle (We vs. I)

As just mentioned, a plan will be developed in cooperation between technology and the stakeholders, based on the baseline and the long-term end goal. Finding the right balance between what is physically and mentally possible for the patient and the partner is crucial to adjust the lifestyle together. For some people, walking 5 km on one day can be a final goal, while for others it is 20 km. There may also be differences between the partner and the patient. The goals of the patient should be leading, but there must also be an opportunity for the partner to contribute with their part in their own way. For this reason, the system must get a realistic picture of the individuals within the couple, after which it offers suggestions (e.g. short term goals, goal revision, objectives, focus) to the couple based on this information (baseline, end goal, physical and mental condition, preferences). Here, the HIP system strives for equality within the relationship concerning the chronic illness. The patient's partner can be encouraged by the patient to achieve the goals and vice versa.

5.2 Recommendation for implementation:

The proposed HIP system serves as a strategic direction and a broadening of the solution direction to involve the partner in the care by means of an eHealth intervention. Due to the 'futuristic' nature of the long-term strategy and its role as a dot on the horizon, it is not realistic to develop and implement this proposed system immediately. To take the first step in this strategic direction, the holistic development approach 'CeHRes Roadmap' by van Gemert-Pijnen et al. (2011) is used. The CeHRes Roadmap is visualised below.
Within this thesis, a robust foundation has been laid for the use of this model. As a next step for the implementation of WeCair and the HIP it is recommended to work towards a Minimal Viable Prototype (MVP). This MVP can be used as a first step and basis for iteratively developing functionalities and validating them during use (operationalisation and summative evaluation) with the stakeholders within the care system. The proposed core elements of the MVP (which are depicted on p. 56-66) are:

- **My Health:** Insight into personal health, lifestyle and through monitoring and self-assessment
- **Our Lifestyle Pathway:** Setting long-term goals together, working towards shared short-term goals to adapt and change lifestyle jointly after the MI
- **How can I help:** Sharing experience, concerns and observations with an AI Agent, by asking questions and answering Experience Sampling questions
- **Heart Knowledge:** Personalized education for the partner

Furthermore, it is recommended to link this partner data stream to the already existing interfaces of patient and healthcare professional.
From this starting point, it is possible to validate assumptions in a lean way (build, test, learn) whether the Hybrid Intelligence Portal actually offers the intended value during the implementation (Ries, 2011). If this is the case, then the platform could be expanded step by step according to the iterative process of van Gemert-Pijnen et al. (2011) towards the previously discussed strategic concept (the dot on the horizon).

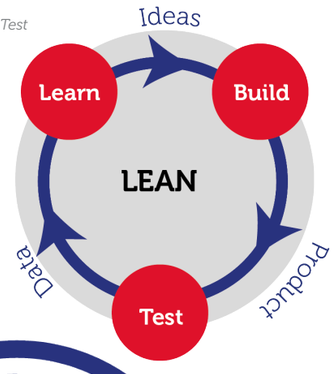


Figure 39. Lean (Build, Test & Learn) by Ries (2011)

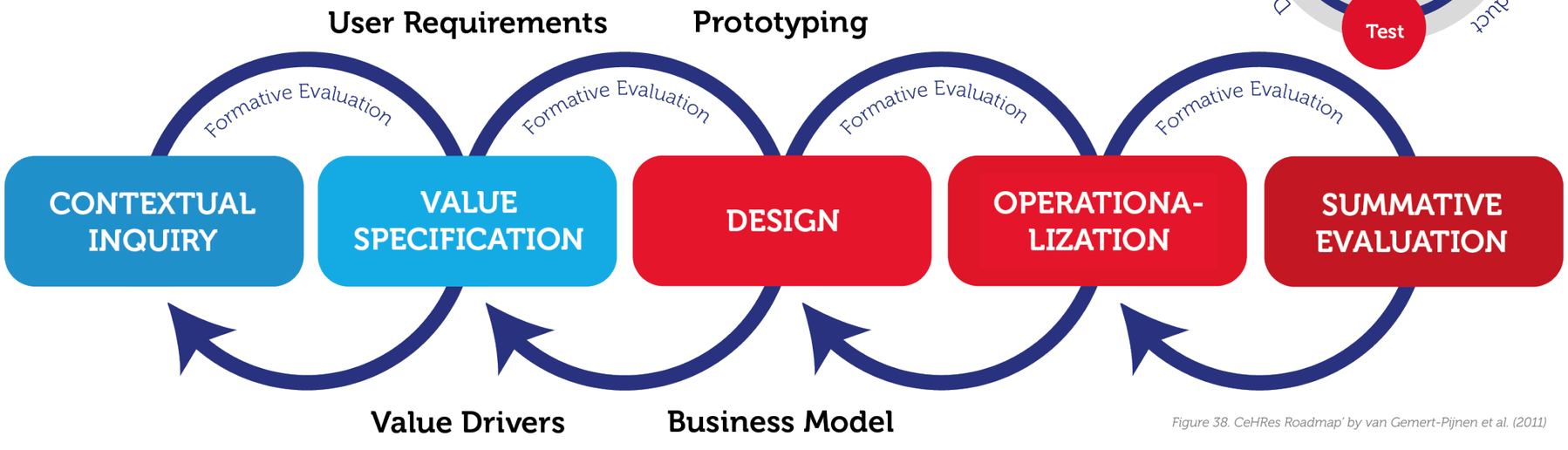


Figure 38. CeHRes Roadmap' by van Gemert-Pijnen et al. (2011)

6. EVALUATE

In this chapter the objectives defined in the introduction will be reflected upon. The Quituple Aim will be used as an evaluation tool to assess whether WeCAIR and the Hybrid Intelligence Portal (HIP) will have a positive effect on the Myocardial Infarction care system of the LUMC Hart Long Centrum. This model will incorporate the desirability, feasibility and viability of the novel long term support & adherence strategy and Product Service System (PSS).

6.1 Quintuple Aim

This section will attempt to determine whether the intended outcome of this project, the meaningful and sustainable improvement of care for MI patients and partners, has been achieved. This will be done by answering the following questions of the Quintuple Aim:

- Does it enhance the patient experience?
- Does it improve the experience of the social context.
- Does it improve population health?
- Does it reduce costs of care?
- Does it improve the wellbeing of care professionals?

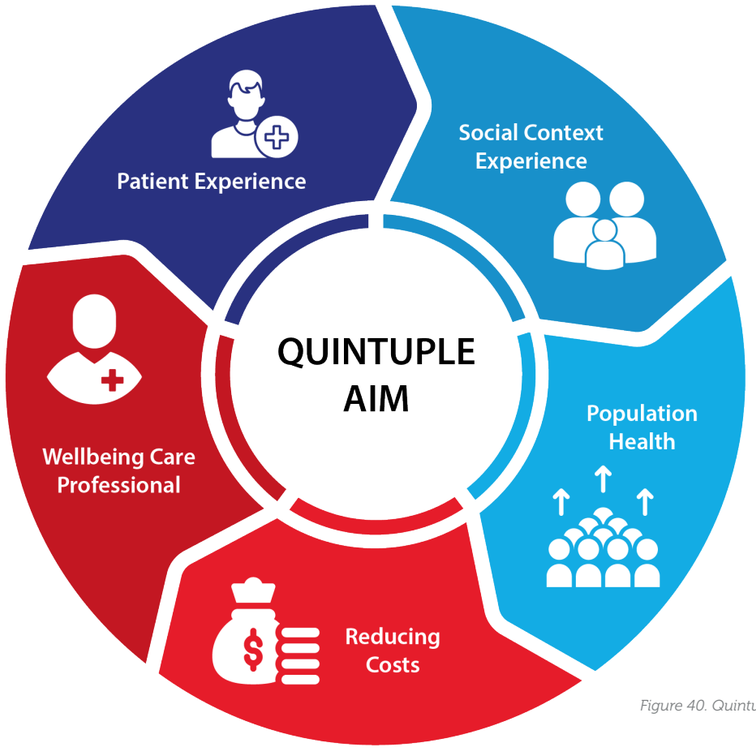


Figure 40. Quintuple Aim

Patient Experience: Does it enhance the patient experience?

WeCAIR and HIP bridge the identified gap (p. 19-23) by providing an alternative care pathway to the current system, thereby improving the patient experience. The implementation of the system would result in adequate support and embedding from the social context, meeting the dynamic physiological and psychosocial needs of the patient. In addition, a clear personalized rehabilitation plan for the short and longer term is developed with a safety net of healthcare professionals, giving the patient a sense of control, safety and certainty (p. 34 & 35). This results in a positive and motivated cooperation within the chronic care towards the future.

Social Context Experience: Does it improve the experience of the social context.

The social context is more an more involved in the disease. One could say that a partner after a MI is a co-patient, because they often bear a significant part of the illness consequences. Adequate participation and support will be increasingly demanded in the future blended care system (p.16-18). WeCAIR facilitates empowerment and guides partners to positively support the patient in the right way at the right moment in changing their lifestyle in the long term. This satisfies the partner's needs of purposeful supporting their loved one and being supported by the care system in 'caring'. The system enhances the partners' experience by balancing the rehabilitation process in a collaborative way, continuously adapting to and learning from the dynamic needs over the longer term.

Population Health: Does it improve population health?

The proposed system has a positive impact on the MI population and the social context surrounding it. By pursuing positive secondary prevention for the patient and primary prevention for the patient's partner, the system facilitates education, better chronic care and a greater percentage of people adhering to long-term lifestyle changes.
Moreover, elements of the WeCAIR and HIP system can be used for other diseases where long-term lifestyle maintenance is relevant. Thus, the underlying principles can also be used to improve care in other populations where partners can provide a supportive role in care.

Reducing Costs: Does it reduce costs of care?

Healthcare costs are reduced by a reduction in the number of relapses and readmissions resulting in a positive return on investment for the proposed system. As patients and partners are monitored at home (physical and psychosocial), risk profiles are compiled. These profiles significantly decrease the frequency of hospital visits, as medical conditions are properly assessed by the healthcare professionals.

Moreover, the technology supports long-term chronic care, allowing better management of the patient and the social context. The goal of WeCAIR and HIP is to reduce healthcare costs while achieving the highest possible value for the patient and partner. The system reduces the burden of care on the healthcare system and gives couples the means to live healthy lives themselves.

Wellbeing Care Professional: Does it improve the wellbeing of health care professionals?

The HIP ensures more effective and efficient care by acting as a 'Balance Guard' that balances the workload for the healthcare professional. By means of risk profiling of patients & couples, and selection of severity, the healthcare professional only intervenes in cases of high risk. This reduces the workload and shifts the responsibility for decision-making in long-term care and cardiovascular risk management partly to the AI Agent technology and the patient's environment. By doing so, the aim is for the quality of care to remain the same or increase.

WeCAIR - Hybrid Intelligence Portal

All in all, it can be concluded that the proposed strategic goal of WeCAIR improves the current care pathway taking into account the Quintuple Aim. For the LUMC Hart Long Centrum, this means that by implementing the Product Service System they will be one step closer to their goal of providing the best clinical and innovative care to patients.

Lastly, it is recommended that in future eHealth innovation, the care system should always involve the social context as an active enabler and participant within the patient care, so that the innovation becomes embedded in the social system around the patient. Do not forget the partner, Do not forget the co-patient.

Figure 41. WeCAIR Evaluation

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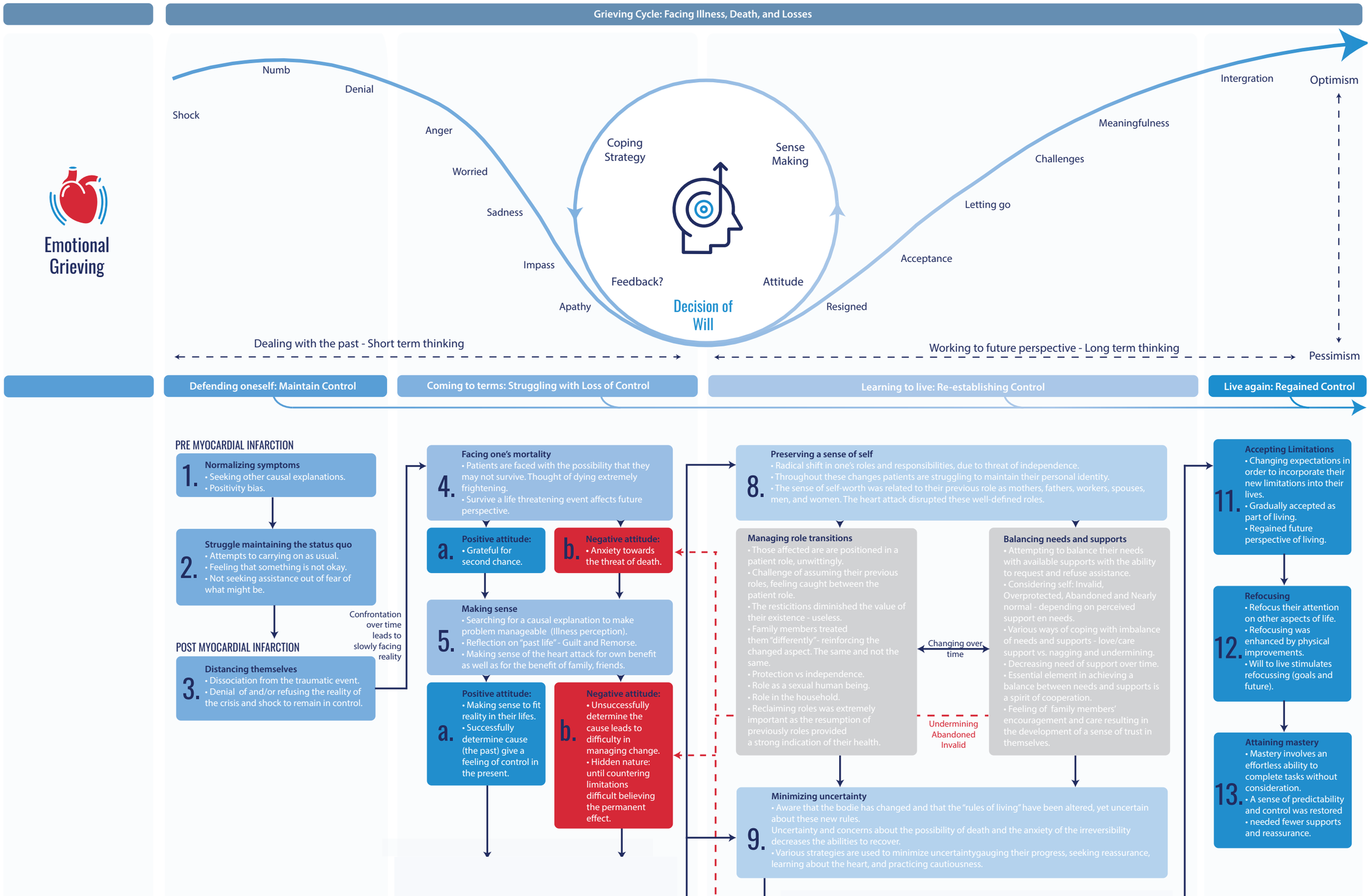
APPENDIX A - PATIENT & PARTNER ADAPTATION PROCESS FOLLOWING A MI



Patient Adaptation: Regaining Control

6. Facing (perceived) limitations
- Consider the implications for the future.
- Coping with fears by "Anticipatory Worrying" to grief perceived losses of their past lives.
- Recognizing that they had to begin to make some life adjustments.

a. Positive attitude:
- Place losses behind them.
- Understanding and attitude towards the future.

b. Negative attitude:
- Limitations perceived insurmountable.
- Fear of permanent disability.

7. Looking to the future
- Future perspective is the most significant factor on the selection of the adjustment strategy.
- Attitude is believed to have the greatest contribution to the adjustment process.
- To groups of attitudes towards the future: Positive Attittude and "Wait and See".

a. "Positive attitude":
- Confidence in recovery.
- "Knowing" the cause.
- "Gratefullness" for second chance.
- Possession of specific plans for rehabilitation.
- Perceptions that limitations are manageable.

b. "Wait & See"
- Fear for permanent disability.
- Inability to understand "why".
- Anger.
- Fear of death.
- Uncertainty to future.
- Reluctance to plans.
- Threshhold.

Failure to achieve set goals

Gauging progress
- Regaining trust and control by provided proof of recovering.
- Establishing a baseline and realistic goalsetting. Working towardsgoals provided a sense of accomplishment structuring the rehabilitation period.
- Able to establish some direction and purpose in their lives.
- "take things one day at a time" - reluctant to make long-term goals, because these often disappoint.
- Reviewing their progress toward resuming normal activities (progress). Time heals aswell.
- Make comparisons with others to remind themselves that their situation could be worse.

Conflict progress perception

Seeking reassurance
- Reassurance was primarily sought from health care professionals - experts.
- Second source are other heart attack vicitims.
- By far the greatest form of reassurance through the cardiac rehabilitation programs. Presence of health care professionals protected them from making errors in judgment
- Health care professionals as sources of reassurance regarding progress: positive and negative effect, due to conflict/similar perception progress.
- Perceptions leading to different believes which influence future perspective: Doing Well - Misunderstoot - Hopelessness - Devastated.

Anxious for all the possibilities

Learning about the heart
- Understanding of the heart enables to understand "what was happening", making the event and the rehabilitation more manageable.
- Especially importent to know what specifically had happened to "their heart".
- This strategy enabled to develop an understanding upon which decisions could be based, however it could also be threatening, the information about the heart.
- For lifestyle adaptation and rehabilitation there is a high need for clear guidelines for what and what not to do in "black and white".

Stuck in fear of over-extertion

Practicing cautiousness
- Ensuring to prevent overactivy, by practicing cautiousness.
- Difficult to make the decision and balance "appropriate level of activity".
- Although they did not want to overexert themselves, they wanted to push themselves toward improvement.
- The fear is able to paralyze: patients can get caught between a desire to "carry on as usual" and a fear that if they did carry on as usual they might hurt themselves and possibly die.

10. Establishing guidelines for living
- After an MI, the patient has the task of reordering his or her life. This objective is accomplished through the establishment of guidelines which reestablishes a sense of control.
- Guidelines for living include an understanding of corporal limitations and an understanding of how one's life will be lived.
- The establishment of guidelines orders an individual's life and therefore enhances his or her sense of predictability, independence, and self-determination.

Confron-tation with slow improve-ment of limitations

Testing limitations
- Once that there is gained confidence in their abilities, patients start to test limitations in order to reestablish a sense of physical control and mastery.
- Testing their limitations in this way contributed to their sense of progress: stretching limits
- Proving to themselves that many of their assumed limitations did not exist, leading to reconsidering the future in a positive matter.

The testing of limitations enabled the informants to regain a sense of predictability and independence, and they learned how to pace themselves. These lessons were only learned through the trial and error testing of their limitations.

hypersen-sitivity and anxie-ty

Learning to read one's body
- In order to overcome the barrier "appropriate level of activity", they were faced with the task of learning to trust their body's abilities.
- This was accomplished by, becoming sensitized to the body's needs and demands.
- The ability to read and trust their bodies was developed over time.
- Sensitivity to their body's abilities enabled them to develop a sense of trust, and this sensitivity provided them with a means by which they could make judgments regarding the continuation of an activity.

Not expe-riencing improve-ments

Modifying life-style
- Involves the serious consideration of life-style changes, attempts to implement and evaluate life-style changes, and, if the outcomes are positive, the incorporation of these changes into one's life
- Decisions regarding life-style modifications are structured by the way in which the individual made sense.
- Life-style changes should be gradual as a "total life adjustment" cannot be implemented quickly.
- The changes considered particularly difficult were those that involved changes in attitude.
- Over the course of repeated testing, the modifications that the informants made became "a part of living."

0. Abandoning the Struggle
- Perpetually caught in the cycle of coming to terms and learning to live and, at times, they find it necessary to abandon the struggle to reestablish control.
- Believe that the fight to regain control is "hopeless."

Partner Adaptation: Rebalancing Normal

Collapse of balance | **Compensating the disbalance** | **Restoring the balance** | **Renewed balance**

1. Life changing event
- Spectrum of shock. Resuscitate partner ⟷ to GP with pain
- Breakdown of the balance of the 'normal life together'.

2. Facing mortality of a loved one
- Emotional rollercoaster.
- Experiencing the impact of the situation.

3. Survival mode
- Being able to do all that is necessary through denial.
- Autopilot - Carry on as "before/normal".

4. Keeping oneself strong for both of you
- The patient is at the centre of the relationship and the partner takes second place.
- Keeping a low profile and not wanting to burden the patient.
- Hiding own emotions to avoid confrontation and try to normalise life.

5. Managing the continuation of life
- Physical continuity of time and context.
- Taking over tasks and the role from the patient.
- Managing household, work, finances, family and all other tasks which continue as usual.

6. Dealing with emotions of uncertainty
- Two parallel emotional experiences, that of the patient and that of the partner. The patient is the focus and a new perspective on the future is being sought.

a. In the foreground
- Dealing with the patient's worries, fears and angry emotions.
- Being a tower of strength for the patient.
- Removing concerns and being there for the patient through support.

b. In the background
- Lonely with own emotions.
- Little room for self-processing of what has happened.
- Feeling guilty when thinking about yourself, because you are not the patient.

7. Balance in the disbalance
- Finding a balance in the imbalance by accepting uncertainty and developing a perspective for the future again.

a. Towards balance
- Has the feeling that the patient is in a positive state of mind.
- Notices that the patient is willing to recover and look positively to the future.
- Feels that the patient accepts the love and help. Looking together at what is possible and feasible.

b. Disbalance
- Suffers from the negativity of the patient/own.
- Is angry that the patient is not trying hard enough to get better.
- Has a negative outlook on the future.
- Focuses only on what has been lost due to the infarction.

8. Rebalancing the relationship and responsibilities
- As the emotions and the physical aspect become more prominent, it is important to rebalance the mutual relationship again.
- It will have to be adapted to the new situation.
- This will be a time of experimentation (trial and error), communication and acceptance/tollerance.

Balancing role transitions
- A balance will also have to be found in the role of the infarct. Is it tackled and dealt with together or is it something that the patient deals with: you or us?
- Role in the household, as a sexual human being and intimacy has changed
- It also happens that the patient's personality changes. There also needs to be some kind of balance for acceptance.
- Important in this phase is to communicate well with each other which can be a challenge.

Changing over time

unvalued, punished

Balancing needs and supports
- For the partner, this is an difficult time. They want to care for their partner out of love, without being able to feel what the patient is experiencing. The partner will have to make an assessment of his/her ability to understand the needs of the partner, which can lead to clashes within the relationship. But this too is necessary to find the balance.
- The way in which and how support can/should be provided is also something that needs to be considered.

9. The act of self-balancing
- Now that the balance is starting to come back and the patient also slowly starts to recover a bit, there is also more and more time and space to deal with own emotions and increasingly bring oneself to the foreground again.
- There are several strategies that can help here: dealing with own emotions, taking care of oneself and suppport for the supporter.

Depressi-on

Dealing with own emotions
- Accept that you may and can be your own person in the relationship with the patient. This becomes easier as the patient gets better.
- There is no need to hide your own feelings and you may go through your own process.
- More and more space is available for you to live your own life and take it up again.
- Time is required to accept the new/adapted life.

Guilty for attention

Taking care of oneself
- Start taking care of yourself again. Focusing less on partners' lives and more on your own. Doing things for yourself again: exercising, picking up hobbies, caring less.
- Good self-care is important for continuing to provide good patient care and to maintain a healthy relationship. Also helps in adjusting the lifestyle.
- Distraction helps with the healing process.

Shame inability

Support for the supporter
- Realises that he/she is not alone and asks/accepts the help of others: family, friends, peers, patient. Consults professional help when necessary.
- Ensures a spread of responsibility and does not try to carry it all on his/her own.
- Shares his/her thoughts and feelings with the patient. Creates an open communication where his/her feelings are "allowed" too.

10. Getting grip on the balance
- Creating a grip by doing as much as possible (in power) on the balancing act of the uncertain future.
- Here, great demands are made upon adaptability, readiness for change and the ability to trust in the future. There are several strategies that can increase these factors: Self-education, Building trust in the partner and Adjusting lifestyle.

Disability to under-stand

Self-education
- Acquiring knowledge about the heart and the patient's condition, so that you know what to expect.
- Involve yourself in the patient's rehabilitation learning process.
- Learning about what you as a partner can actively participate in the recovery process to make it as successful as possible.

Fear of harm

Recovering trust in patient's body
- Trusting that the patient is capable of taking care of himself and feel his limits.
- Doing rehabilitation activities together and experimenting by building up in order to get to know the patient's (new) body better.
- Learning and knowing the patient's limits.

Faillure to commit

Adjusting Lifestyle
- Secondary prevention as a way to gauge whether you are doing everything possible to prevent a reoccurrence and balance the control one has over the future.
- Monitoring progress to see that investing the effort works.
- Setting and reflecting on common goals. Encouraging each other positively to achieve them.

11. New normal
- Adjusted to the life-changes.
- Working diadic system at home in terms of communication and roles.
- Integration of lifestyle adjustments

12. Focusing on possibilities
- Focussing on what is still possible in the life together
- Enjoying life to the fullest because accepted that life is unpredictable.
- Being content together

13. Part of life
- We have a positive attitude to life and look forward to a happy and hopeful future together

0. Abandoning the Struggle
- Giving up hope in the partner and the future together. For these reasons living together unhappily or escaping from the high stressor

APPENDIX B1 - ILLNESS PERCEPTION QUESTIONNAIRE

This questionnaire can also be rewritten to one that provides insight into the partner's perception of illness.
Weinman, Petrie, Moss-Morris & Horne (1996)

	I have experienced this symptom since *my illness*		This symptom is *related to my illness*	
Pain	Yes	No	Yes	No
Nausea	Yes	No	Yes	No
Breathlessness	Yes	No	Yes	No
Weight Loss	Yes	No	Yes	No
Fatigue	Yes	No	Yes	No
Stiff Joints	Yes	No	Yes	No
Sore Eyes	Yes	No	Yes	No
Headaches	Yes	No	Yes	No
Upset Stomach	Yes	No	Yes	No
Sleep Difficulties	Yes	No	Yes	No
Dizziness	Yes	No	Yes	No
Loss of Strength	Yes	No	Yes	No

Listed below are a number of symptoms that you may or may not have experienced since your illness. Please indicate by circling Yes or No, whether you have experienced any of these symptoms since your illness, and whether you believe that these symptoms are related to your illness.

	VIEWS ABOUT YOUR ILLNESS	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONLGY AGREE
IP1	My illness will last a short time					
IP2	My illness is likely to be permanent ratherthan temporary					
IP3	My illness will last for a long time					
IP4*	This illness will pass quickly					
IP5	I expect to have this illness for the rest of mylife					
IP6	My illness is a serious condition					
IP7	My illness has major consequences on my life					
IP8	My illness is easy to live with					
IP10	My illness strongly affects the way others seeme					
IP11	My illness has serious financial consequences					
IP13*	My illness causes difficulties for those whoare close to me					
IP17	There is a lot which I can do to control my symptoms					
IP18	What I do can determine whether my illnessgets better or worse					
IP20*	The course of my illness depends on me					
IP21*	Nothing I do will affect my illness					
IP22*	I have the power to influence my illness					
IP23*	My actions will have no affect on the outcomeof my illness					
IP26	My illness will improve in time					
IP27	There is very little that can be done toimprove my illness					
IP28*	My treatment will be effective in curing myillness					
IP29*	Negative effects of my illness can be prevented (avoided) by my treatment					
IP30*	My treatment can control my illness					
IP31*	There is nothing which can help my condition					
IP32	The symptoms of my condition are puzzlingto me					

	VIEWS ABOUT YOUR ILLNESS	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONLGY AGREE
IP33	My illness is a mystery to me					
IP34*	I don't understand my illness					
IP35*	My illness doesn't make any sense to me					
IP36*	I have a clear picture or understanding of my condition					
IP37	The symptoms of my illness change a great deal from day to day					
IP38*	My symptoms come and go in cycles					
IP39*	My illness is very unpredictable					
IP41*	I go through cycles in which my illness gets better and worse.					
IP44	I get depressed when I think about my illness					
IP45*	When I think about my illness I get upset					
IP46*	My illness makes me feel angry					
IP47*	My illness does not worry me					
IP48*	Having this illness makes me feel anxious					
IP50*	My illness makes me feel afraid					

IP33 My illness is a mystery to me
IP34* I don't understand my illness
IP35* My illness doesn't make any sense to me
IP36* I have a clear picture or understanding of my condition
IP37 The symptoms of my illness change a great deal from day to day
IP38* My symptoms come and go in cycles
IP39* My illness is very unpredictable
IP41* I go through cycles in which my illness gets better and worse.
IP44 I get depressed when I think about my illness
IP45* When I think about my illness I get upset

	POSSIBLE CAUSES	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONLGY AGREE
C1	Stress or worry					
C2	Hereditary - it runs in my family					
C3	A Germ or virus					
C4	Diet or eating habits					
C5	Chance or bad luck					
C6	Poor medical care in my past					
C7	Pollution in the environment					
C8	My own behaviour					
C9	My mental attitude e.g. thinking about life negatively					
C10	Family problems or worries					
C11*	Overwork					
C12*	My emotional state e.g. feeling down, lonely, anxious, empty					
C13*	Ageing					
C16*	Accident or injury					
C17*	My personality					
C18*	Altered immunity					

CAUSES OF MY ILLNESS

We are interested in what you consider may have been the cause of your illness. As people are very different, there is no correct answer for this question. We are most interested in your own views about the factors that caused your illness rather than what others including doctors or family may have suggested to you. Below is a list of possible causes for your illness. Please indicate how much you agree or disagree that they were causes for you by ticking the appropriate box.

In the table above, please list in rank-order the three most important factors that you now believe caused YOUR ILLNESS. You may use any of the items from the box above, or you may have additional ideas of your own. The most important causes for me:

1. ……

2. ……

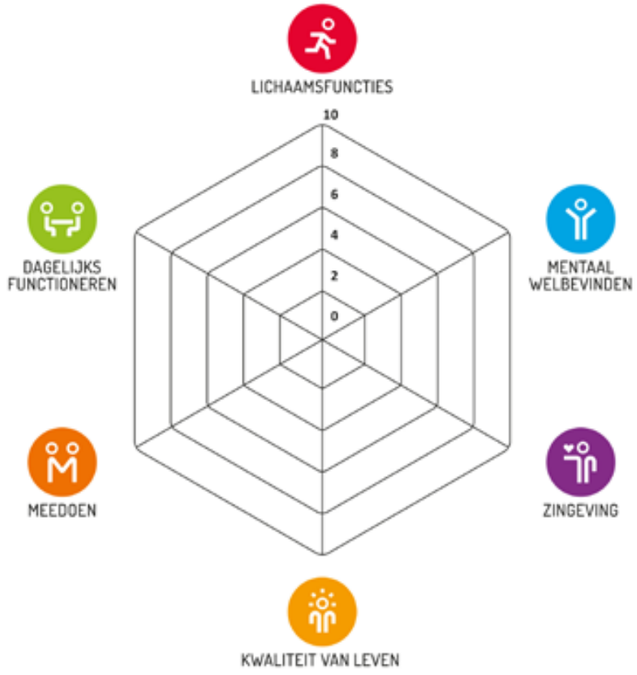
3. ……

APPENDIX B2 - POSITIVE HEALTH QUESTIONNAIRE

Huber et al. (2011)

Mensen met ervaring met ziekte zien gezondheid heel breed, veel breder dan alleen de lichamelijke kant, zo blijkt uit wetenschappelijk onderzoek. Deze brede kijk is 'Positieve Gezondheid' genoemd en omvat zes gebieden.

Geef uzelf een rapportcijfer en neem dit cijfer over in het spinnenweb hiernaast. Zo ontstaat uw eigen gezondheid oppervlakte. Beantwoord vervolgens de vraag "Waar ziet uzelf mogelijkheden voor verbetering?



Ik voel mij gezond
- Je gezond voelen
- Fitheid
- Klachten en pijn
- Slapen
- Eten
- Conditie
- Bewegen

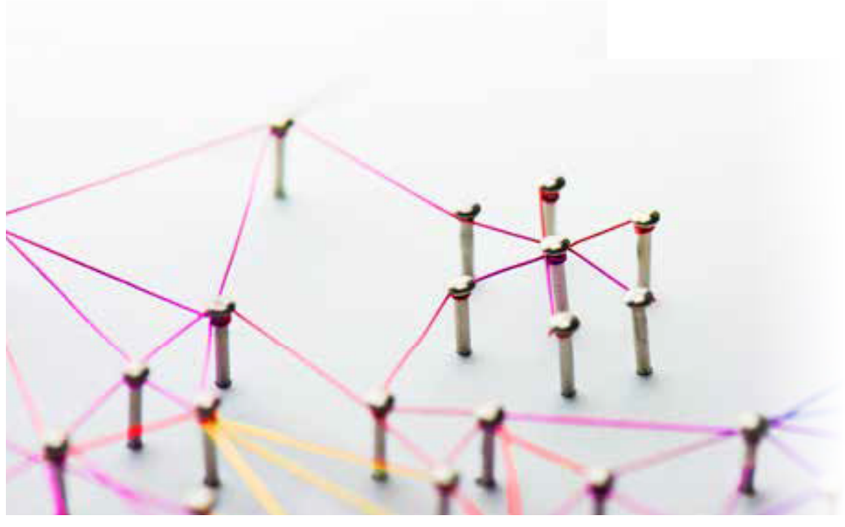
Ik heb vertrouwen in mijn eigen toekomst
- Zinvol leven
- Levenslust
- Idealen willen bereiken
- Vertrouwen hebben
- Accepteren
- Dankbaarheid
- Blijven leren

Ik heb goed contact met andere mensen
- Sociale contacten
- Serieus genomen worden
- Samen leuke dingen doen
- Steun van anderen
- Erbij horen
- Zinvolle dingen doen
- Interesse in de maatschappij

Ik geniet van mijn leven
- Genieten
- Gelukkig zijn
- Lekker in je vel zitten
- Balans
- Je veilig voelen
- Hoe je woont
- Rondkomen met je geld

Ik voel mij vrolijk
- Onthouden
- Concentreren
- Communiceren
- Vrolijk zijn
- Jezelf accepteren
- Omgaan met verandering
- Gevoel van controle

Ik kan goed voor mijzelf zorgen
- Zorgen voor jezelf
- Je grenzen kennen
- Kennis van gezondheid
- Omgaan met tijd
- Omgaan met geld
- Kunnen werken
- Hulp kunnen vragen



APPENDIX B3 - QUESTIONNAIRE FOR MEASURING DEPRESSION, ANXIETY AND STRESS

de Beurs, van Dyck, Marquenie, Lange, & Blonk (2001)

DASS Naam: Datum:

Geef voor ieder van de onderstaande uitspraken aan in hoeverre de uitspraak de afgelopen week voor u van toepassing was door een nummer te omcirkelen.Er zijn geen goede of foute antwoorden. Besteed niet te veel tijd aan iedere uitspraak, het gaat om uw eerste indruk.
De nummers hebben deze betekenis:

0 = Helemaal niet of nooit van toepassing
1 = Een beetje of soms van toepassing
2 = Behoorlijk of vaak van toepassing
3 = Zeer zeker of meestal van toepassing

1	Ik merkte dat ik overstuur raakte van onbelangrijke zaken	0	1	2	3
2	Ik merkte dat mijn mond droog aanvoelde	0	1	2	3
3	Ik was niet in staat om ook maar enig positief gevoel te ervaren	0	1	2	3
4	Ik had moeite met ademhalen (bijv. overmatig snel ademen, buitenadem zijn zonder me in te spannen)	0	1	2	3
5	Ik kon maar niet op gang komen	0	1	2	3
6	Ik had de neiging om overdreven te reageren op situaties	0	1	2	3
7	Ik voelde me beverig (bijv. onvast ter been zijn)	0	1	2	3
8	Ik vond het moeilijk me te ontspannen	0	1	2	3
9	Er waren situaties die me zo angstig maakten dat ik erg opgelucht waswanneer het ophield	0	1	2	3
10	Ik had het gevoel dat ik niets had om naar uit te kijken	0	1	2	3
11	Ik merkte dat ik gemakkelijk overstuur raakte	0	1	2	3
12	Ik was erg opgefokt	0	1	2	3
13	Ik voelde me verdrietig en depressief	0	1	2	3
14	Ik merkte dat ik erg ongeduldig werd van oponthoud (bijv. wachten opeen lift, stoplichten, file)	0	1	2	3
15	Ik had het gevoel flauw te gaan vallen	0	1	2	3
16	Ik had mijn interesse in zo'n beetje alles verloren	0	1	2	3
17	Ik had het gevoel dat ik als persoon niet veel voorstel	0	1	2	3
18	Ik merkte dat ik nogal licht geraakt was	0	1	2	3
19	Ik transpireerde merkbaar (bijv. zweethanden) terwijl het niet warmwas en ik me niet inspande	0	1	2	3
20	Ik was angstig zonder enige reden	0	1	2	3
21	Ik had het gevoel dat mijn leven niet de moeite waard is	0	1	2	3

DASS

De nummers hebben deze betekenis:

0 = Helemaal niet of nooit van toepassing
1 = Een beetje of soms van toepassing
2 = Behoorlijk of vaak van toepassing
3 = Zeer zeker of meestal van toepassing

22	Ik vond het moeilijk op verhaal te komen	0	1	2	3
23	Ik had moeite met slikken	0	1	2	3
24	Ik was niet in staat om enig plezier te hebben bij wat ik deed	0	1	2	3
25	Ik was me bewust van mijn hartslag terwijl ik me niet fysiek inspande (bijv. het gevoel van een versnelde hartslag of het overslaan van hethart)	0	1	2	3
26	Ik voelde me somber en zwaarmoedig	0	1	2	3
27	Ik merkte dat ik erg snel prikkelbaar was	0	1	2	3
28	Ik had het gevoel dat ik bijna in paniek raakte	0	1	2	3
29	Ik vond het moeilijk tot rust te komen nadat iets me overstuur hadgemaakt	0	1	2	3
30	Ik was bang dat ik van mijn stuk zou raken bij een eenvoudige nieuwebezigheid of taak	0	1	2	3
31	Ik was niet in staat om over ook maar iets enthousiast te worden	0	1	2	3
32	Ik vond het moeilijk om te dulden dat ik gestoord werd bij wat ik aanhet doen was	0	1	2	3
33	Ik was erg nerveus	0	1	2	3
34	Ik had het gevoel niets waard te zijn	0	1	2	3
35	Ik had volstrekt geen geduld met dingen die me hinderden bij iets datik wilde doen	0	1	2	3
36	Ik voelde me ontzettend angstig	0	1	2	3
37	Ik kon niets in de toekomst zien om me op te verheugen	0	1	2	3
38	Ik had het gevoel dat mijn leven geen zin had	0	1	2	3
39	Ik merkte dat ik erg onrustig was	0	1	2	3
40	Ik maakte me zorgen over situaties waarin ik in paniek zou raken enmezelf belachelijk zou maken	0	1	2	3

Experiencing a Myocardial Infarction together.

Partner as co-patient in lifestyle change