Redesigning cardiovascular healthcare: patient and professional perspectives on value

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CHAPTER IX

SUMMARY, CONCLUDING REMARKS AND FUTURE PERSPECTIVES

In this thesis, two research methods are used to systematically evaluate patterns of national and local cardiovascular care to improve it further. The introduction (**chapter I**) describes the general outline of the thesis. A definition of evidence based cardiovascular medicine and its value as seen by the professional, is discussed. Value Based Healthcare research, which prioritizes the *patient* perspective of value and outcome, is offered as a valuable addition to improve clinical care. In line with this, a systematic approach to evaluate and modify cardiovascular healthcare on a national level for the professional is stressed in **Part I**. For both the professional and patient, **Part II** describes research to improve local (i.e. hospital) cardiovascular care. Both parts combined, provide a holistic framework to improve clinical work on multiple levels.

The first part of the introduction describes how value in cardiovascular care is defined by the modern-day professional via evidence based medicine and clinical guidelines. **Chapters II and III** illustrate the disparities between 'guideline recommendation' and 'real world patterns' regarding treatment of myocardial infarction patients in the Netherlands.

Results are discussed of two studies using national-, and regional claims data to find modifiable factors in the treatment of myocardial infarction patients. The second part of the introduction describes the multilayered concepts of 'health' and 'value' for the professional and patient, within the framework of Value Based Healthcare as described by Porter and Teisberg. The principles of Human Factors (HF) science are described, which provides a fruitful addition in Value Based Healthcare research of cardiovascular patients. **Chapters IV to VIII** describe various studies concerning HF science, its methodology and the utilization of this type of research in clinical cardiovascular care. Below, all individual chapters of parts I and II are described in detail.

Part One – Claims Data Analysis

Chapter II describes the use of claims data to assess treatment of non ST elevation myocardial infarction (NSTEMI) patients in the Netherlands. The aim of the study was to search for modifiable factors to improve Dutch NSTEMI care.

For that reason, real world data was compared to guideline recommendations regarding revascularization via percutaneous intervention (PCI) and secondary preventive medication. Claims data of almost 18,000 unique (i.e. ever first) NSTEMI patients treated in Dutch hospitals in 2015 was analyzed. PCI use within 72hours during hospitalization and total secondary preventive medication use (combined use of aspirin-specie, P2Y12-inhibitor, betablocker, ACE/AT-II inhibitor, and statin) during 30 days follow-up were assessed.

Via propensity score matching, the effect of PCI, and optimal medical treatment on one year mortality were calculated. Less than half of all NSTEMI patients (43%) received a PCI during hospitalization within 72hrs. Identically, less than half (47%) of all NSTEMI patients had optimal medical therapy after 30 days of the initial NSTEMI. Having had a PCI within 72hrs of hospitalization and having had optimal medical therapy at 30days, were both associated with lower 1-year mortality (respectively OR 0.42; 95%CI 0.37-0.48 and OR 0.59; 95%CI 0.51-67). The presented study highlights the usefulness of claims data in regard to the evaluation of real-world care in a large cohort of NSTEMI patients with data of past years with minimal registrational burden.

The results aid cardiologists by stressing awareness for thorough evaluation of revascularization options and strive for complete medical adherence in NSTEMI patients.

Chapter III investigates the use of claims data combined with open-access governmental socioeconomic status statistics on a zip-code level to assess myocardial infarction care on a regional level of three Dutch hospitals. Almost 3,200 patients were included.

Total revascularization- (PCI and CABG), optimal medical therapy- and mortality patterns were assessed among ST elevation myocardial infarction (STEMI)- and NSTEMI patients. The study showed that low SES STEMI and NSTEMI patients more often receive a CABG and more often use complete optimal medical therapy after myocardial infarction. No mortality differences were observed. This proof-of-concept study shows that claims data can be effectively coupled to zip-code socioeconomic statistics to asses regional myocardial infarction care and provide specific recommendations to improve care on a zip-code level.

This enables care givers to focus for instance on primary prevention strategies in low-income areas or on secondary prevention awareness campaigns in wealthier neighborhoods.

Part Two – Human Factors Science in Cardiovascular Care

Chapter IV describes an editorial which introduces the concept of Human Factors (HF) science into the domain of cardiovascular healthcare to support research in line with Value Based Healthcare principles and optimize care processes for both the professional and patient.

Chapter V discusses the results of a study implementing a common aviation HF questionnaire (Safety Attitudes Questionnaire -SAQ) to measure and understand the safety climate of two teams performing open- and endovascular repair of complex aortic aneurysms.

This qualitative study shows that the SAQ is an effective screening tool to assess local safety culture of surgical teams and hint at suggestions to improve interprofessional collaboration between physicians and support-personnel to optimize patient safety during procedures.

Chapter VI outlines HF research to assess outpatient education of myocardial infarction patients to eventually develop a Mixed Reality Hololens application to support this process. Twelve patients and six healthcare professionals were randomly included in this qualitative interview study. Patients and professionals were asked on the importance of educational topics (anatomy, medication, rehabilitation, personal life). Provided information to all patients was perceived as being too extensive, incoherent and difficult to comprehend, especially regarding the importance of secondary preventive medication. Although rated by the professional as being of importance, patients indicated that little attention was given by the healthcare provider to address the impact of medication use on personal life. On the contrary, professionals noted that there should be more education on anatomical aspects of myocardial infarction and secondary prevention. The findings of this study strikingly highlight the disparities between patient-, and professional perspectives on the subject of education, which should be an eye-opener to clinicians.

The Microsoft™ HoloLens was proposed as an educational tool, capable of uniting patient and professional perspectives on for instance secondary preventive medication.

Chapter VII extends the findings of chapter VI into a controlled clinical study, by designing a working MR model to educate the importance of statins to myocardial infarction patients.

A human centered design approach was used, novel in the field of clinical cardiology. Effects of conventional education (verbal education, booklets) on statin knowledge were assessed in 10 STEMI and NSTEMI patients. This was compared to the effect of an MR-statin model on statin knowledge in 12 STEMI and NSTEMI patients. The study shows that conventional education only has little impact on statin understanding, while the HoloLens statin model is effective in teaching patients the importance of statins and may promote learning over time.

Both **chapters VI and VII** showcase the usefulness of combining HF design-thinking and scientific evaluation into a fluid process. **Chapter VIII** focusses on the patient perspective of a pre-cardiac catheterization Virtual Reality application for outpatient care.

The study primarily assess the acceptability and feasibility of an alpha version of a VR application called ‘Pre-View’ in patients receiving elective cardiac catheterization. Identical to chapter VII, a design-thinking approach was used to evaluate the VR application to improve it further.

The application shows patients the hospital admission via interactive 360- degrees photos and videos. A small patient population (N=8) tested the application in the outpatient setting before cardiac catheterization, which showed that patients felt overall informed with a high sense of participation in the care-process and being highly involved in the application with only minimal side-effects (i.e. cybersickness). Despite the small study population, the study shows that VR is an acceptable medium in the outpatient setting of cardiovascular care, enabling new possibilities for patient education.

Concluding Remarks and Future Perspectives

This thesis discussed a systematic approach to evaluate value in clinical cardiovascular care on multiple levels and how to improve it further. Common treatment patterns of nationwide myocardial infarction care were assessed as well as the evaluation and re-design of clinical collaboration between professionals during aortic surgery and outpatient care of myocardial infarction patients. Although evidence based choices are present in clinical work, the presented studies stress the reality of Dutch clinical cardiovascular care in the 21st century. They demonstrate the tension between, on the one hand, professionals who try to follow guideline-treatment in order to optimize clinical outcome and, on the other hand, patients who also experience healthcare on a more qualitative and less quantifiable level. Overall, claims data analysis and HF research are both methodologies that provide a unique framework to investigate and improve care processes for both the patient and professional in cardiovascular care.

Data Driven Healthcare

In the Netherlands, hospitals are committed to collect and register encrypted quality-of-care patient data to monitor and assess care provided to patients(1-3). This provides transparency of delivered care and the possibility to evaluate outcomes of various patient categories(4).

For cardiovascular care, The Dutch cardiovascular quality of care registry (Nederlandse Hart Registratie, NHR) is an important example(5). The collection, storage and maintenance is predominantly driven by professionals (i.e. thoracic surgeons, cardiologists) to evaluate treatment patterns on a national level, as well as patient survival or the occurrence of adverse events. In more recent years, claims data is seen as a valuable source of data for quality assessment in various disciplines such as cardiology(6-10), pulmonology(11-13), nephrology(14, 15), and oncology(16-19).

Apart from quality assessment, claims data analysis offers a prolific addition to clinical research to assess healthcare and provide insight in patient numbers, treatment patterns over various years and demographic entities.

Compared to common, observational registry studies, claims data analysis is predominantly retrospective, with a low registrational burden as this data is automatically coupled to governmental data and logged/stored after patients' hospital discharge.

It reflects 'real world' patterns and evidence rather than data from randomized studies which is highly dependable on in- or exclusion criteria(13, 20, 21). Nonetheless, important shortcomings are the lack of clinical details such as journal entries, laboratory findings or imaging data and the fact that all claims data are stored at insurance company data centers, not rapidly available to physicians.

For future purposes, a coupling of claims data and clinical data may further support the clinical use of it. A hybrid system of claims data coupled to clinical data, generated and stored *at hospitals,* might be a solution to improve availability for research, and thus eventually support the creation of clinical guidelines.

With an expanding global population of patients and the endless possibilities to generate and store data in modern medicine, healthcare becomes more 'data-driven'(22-24).

Identically, as the quality of the data stored becomes better and more complete, the possibilities in clinical medicine expand such as the development of Artificial Intelligence (AI) (25-27). To improve the use of clinical data overall, the generation and storage of it as well as the availability of the data to professional and patient, should be a focus of development in the future with the electronic medical record (EMR) as the backbone(28). The EMR as the daily digital work environment of modern healthcare, provides a useful foundation of data formation, storage, access and analysis.

To improve the usefulness of this clinical data, a strong position by professional societies, even in governance, is crucial in my opinion. Firstly to determine for what purpose/meaning data should be collected and secondly, to create more unity in the generation, storage and usability of clinical data in modern medicine.

Human Factors in Cardiovascular Care – Meta Value

Although novel in cardiovascular research, HF science is a discipline which increasingly finds its way into medical care(29-34).
Cardiovascular care being heavily reliant on human physical- and cognitive performance in a complex environment, can benefit from HF science on multiple levels. Not only in sole diagnostic- or curative domains but also on the organizational level. Especially in the development and usability of novel technologies in clinical care as proposed in part two of this thesis, HF science offers a novel approach to change and hopefully improve cardiovascular healthcare in a meaningful way for both the patient and professional.

In recent years, implementation of electronic- or mobile health (eHealth, mHealth) into cardiovascular healthcare has gained increased attention. Electronic devices become more and more present in daily life and clinical care, which expand the possibilities in modern healthcare for both the patient and professional(35-38).

Traditional physical check-ups are exchanged for video conferences with physicians(39, 40) and the use of wearable Bluetooth™ devices such as blood pressure monitors or ECG-devices enable the professional to closely monitor the patient at home, and interfere when necessary(41, 42). Moreover, these devices enable certain patient 'empowerment' with a positive impact on overall health(43). However, although the interaction between humans (patients) and technology is perceived as something that just 'is', it is worth investigating *how* this interaction is perceived and where the true value lies for the individual.

In cardiovascular medicine, professionals and patients are overall positive about the potential of eHealth(44-46), however little is known what effect of this technological transition has on an ever growing, elderly, patient population in terms of psychological stress or anxiety, as evidence is limited(47). Technological advancements in cardiovascular science show an exponential growth yearly(48), however as humans, our biology and psychology are not altered in a similar way. A good example among the young is an increased level of anxiety and depression among frequent users of novel social media applications and modern mobile technology(49-51). Studies examining the impact of eHealth on psychological wellbeing in cardiovascular patients are scarce today.

HF science can be a valuable addition to systematically understand the (psychological) impact of technological advancements such as eHealth, and simultaneously offer a method to develop and implement new devices and technology in line with patient and professional preferences.

Especially the use of a patient-experience journey as proposed in this thesis, is essential in understanding the many elements of clinical care of which daily work consists, such as the interaction with the professional and the impact on the patient. From a VBHC perspective, outcomes on a personal level become thus more transparent and quantifiable(33, 34, 52).

Furthermore, this process of mapping the healthcare experience by placing the human at the center of it, has become refined not only to support the utilization of novel devices in clinical care, but identically in the development of care tracks across multiple domains of healthcare(33, 53, 54).

The strength of this process lies not only in the fact that it helps understand how stakeholders perceive and value the implementation of new elements of care, but also how the whole care-track can be redesigned by using this input. Regarding VBHC, this methodology enables a focus on value on a *meta-level*. Many dimensions of human health, disease and outcomes create an interaction with healthcare, not a single encounter.

Using HF science and predominantly patient experience mapping supports the view that designing care is not merely for one aspect of disease. HF science in a sense, paves the way to healthcare design becoming more focused around the care continuum of chronic ailments, of which cardiovascular disease is a large part. A close collaboration between patients and medical professionals is eminent in this process.
Despite some studies in this thesis having a small study population, meaningful information can still be gathered using a structured systematic analysis such as the patient journey/ experience mapping offers.

An interesting next step in human centered design and patient experience mapping, can be a focus on the permanency of the disease and care processes when re-designing healthcare. Cardiovascular disease is foremost a chronic ailment, which leads to suffering longitudinally on a physical and emotional level(55). 'Empowering' the patient by actively pursuing self-management and autonomy, can improve the perceptions regarding treatment and outcome, which in turn, lead to improved life expectancy(56). To empower, it is crucial to understand how patients perceive their illness in terms of coping and what they expect from treatment(57), but identically how they perceive their health in general(58). As a foundation, these illness and health perceptions can steer research and eventually let outcomes become more patient and value driven. In my opinion, to achieve this and to embed principles of human centered design and HF science further in modern cardiovascular research, a partnership with professionals from other disciplines such as humanities, design and technology will be crucial for the evolution of cardiovascular healthcare in the 21st century, to ensure a broad scientific basis.

To improve quality of clinical care and research, thorough evaluation of the scientific processes on usability, meaning and value should be done on regular basis, not only by professionals, but equally patients. Thus creating a loop of continued improvement (figure 1). Incorporating HF scientists in the foundation of this process within modern hospitals and clinical research creates hybrid care-centers with diverse specialists, which opens new possibilities in the future development of cardiovascular care. Designed by humans, for humans.

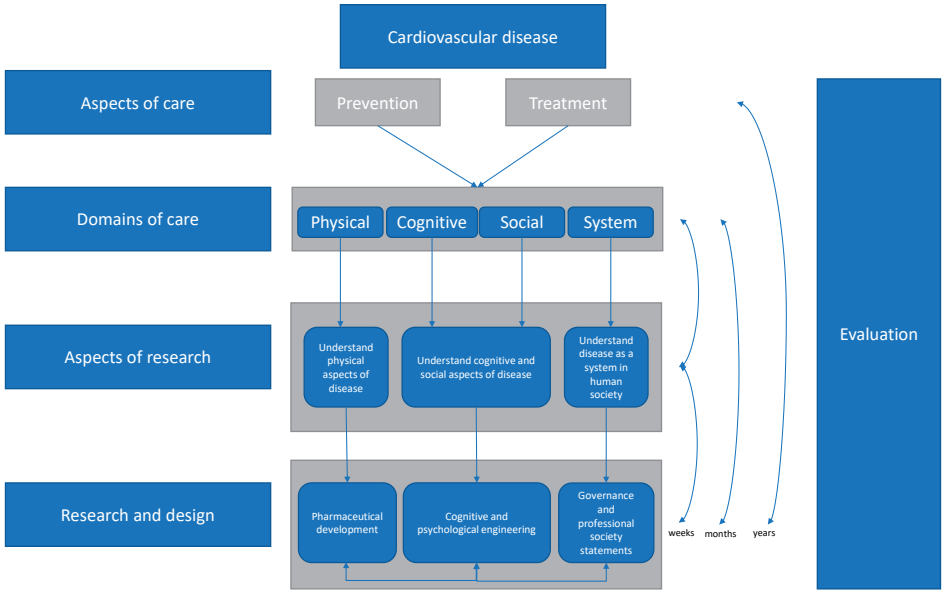

Figure 1. The future of cardiovascular care and scientific research.

Legend: To ensure a continuous system of improvement of daily clinical care and scientific research, Human Factors science provides a holistic approach to develop complex systems such as cardiovascular healthcare. At the basis should be thorough evaluation of research,- and design elements on personal and system levels, creating a continued loop of improvement.

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