

The PROMise of remote monitoring to improve quality of care for inflammatory bowel disease

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VALORISATION

Inflammatory bowel disease (IBD) is a chronic heterogeneous condition of the gastrointestinal tract that requires life-long continuous and tight monitoring to prevent complications such as fistulae, abscesses, surgeries and hospitalisations. The disease itself and especially these complications are responsible for a diminished quality of life in IBD patients. In the current traditional overburdened outpatient setting, implementation of a tight control strategy is challenging and costly. Optimisation of quality of care is an important task of healthcare professionals and facilities but due to increasing healthcare expenditures, professionals are stimulated to develop innovative and creative ideas to improve outcome and quality of care but control costs. This thesis showed that telemedicine enables implementation of a tight control strategy resulting in better health outcomes without increasing healthcare costs.

Value for patients

Value of care for patients is determined by two factors: health outcomes and healthcare costs¹. This thesis showed that both factors were positively influenced by the use of telemedicine. The myIBDcoach trial showed that care via telemedicine contributed to strict monitoring and instantaneous action in case of a relapse. Most probably this was responsible for the 50% reduction in hospitalisations and thereby better health outcome. As expected, incorporation of telemedicine in IBD-care resulted in cost-savings. Furthermore, patients reported that myIBDcoach resulted in time-savings because they only had to visit the hospital when necessary and they could fill out monitoring sessions at a for them convenient moment and location. A recently performed survey among 7500 IBD patients highlighted 5 areas related to quality of IBD care from the patients' perspective: (1) quality of specialist communication, (2) whether the review consultation was long enough, (3) failure to share information in the past 2 years, (4) no access to a dietitian and (5) speed of advice in case of flare². As patients were involved in this project from the early beginning, myIBDcoach also monitors outcomes that matter most to them, such as quality of life, nutrition, (work)disability and psychological problems. Monitoring on these aspects enables professionals to implement a more personalised and holistic treatment approach with targeted interventions, such as a referral to physiotherapists, dietitian or a psychologist. We furthermore expect that due to the information function of myIBDcoach and due to insight in their personal care plan, patients' self-management and empowerment will be improved. From the literature, we know that this positively influences quality of

Patient: MyIBDcoach helps to keep track of my illness and I can find information easily. If it goes bad, the line with your doctor is very short and prevents you from waiting too long with serious complaints. By intervening more quickly on an approaching flare, you will prevent yourself from becoming seriously ill. That greatly improves quality of life.

life. Patients furthermore experienced an easy and effective way of communication with their healthcare providers through myIBDcoach. We believe that broad implementation of telemedicine in parallel with reorganisation of care can further improve long-term disease outcome and thereby patients' quality of life. We had an intensive collaboration with patients during the different phases of this project, and close contact with the patient organisation CCUVN. The fact that we easily included 909 patients in the myIBDcoach trial, underscores that myIBDcoach is of value for IBD patients.

Value for healthcare professionals

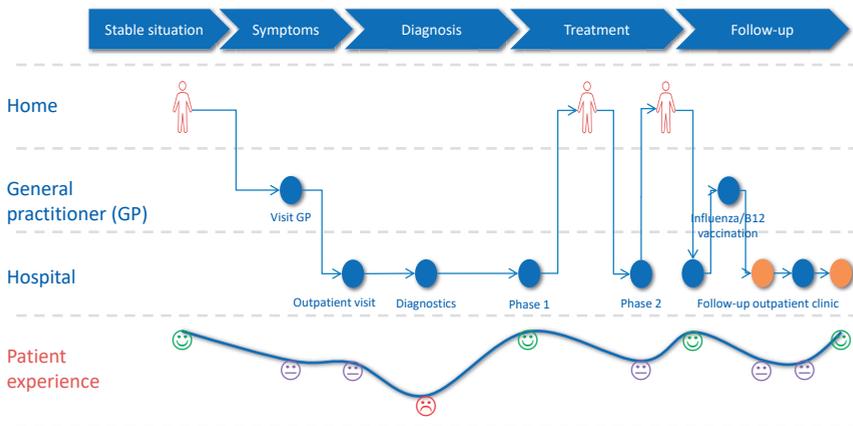
Improving quality and value of care is a continuous task for every healthcare professional. To achieve better health outcomes, recent studies show that patients' symptoms and mucosal inflammation need to be tracked closely. Close disease monitoring in a traditional healthcare setting is however challenging due to limited medical and financial resources and more so since the incidence of IBD is increasing. Additionally, due to increasing healthcare costs, healthcare professionals are forced to register disease outcomes and quality parameters increasing the administrative burden. In this regard, telemedicine tools are valuable for monitoring patients at home between outpatient visits and assist healthcare professionals in implementing such a tight control strategy and for automatic registration of quality parameters.

This thesis showed that telemonitoring in combination with patient-tailored information, a personal care plan, and easy, accessible contact with the IBD nurse, resulted in a reduction of healthcare utilisation and hospital admissions and thereby in costs. Additionally, IBD telemanagement creates fast access to healthcare professionals and frees up capacity at the outpatient clinics for those patients with complex disease or in need of urgent action. Furthermore, myIBDcoach focuses on all aspects of this complex disease correlated with the disease course, such as smoking, medication adherence, nutrition or psychological factors. These aspects tend to receive little attention during traditional outpatient visits. Patients using myIBDcoach receive a questionnaire prior to an outpatient visit, including the IBD control questionnaire, which is a sensitive instrument for measuring overall disease control from the patients' perspective, and the "Lastmeter", which is a questionnaire that indicates if there are any inconveniences on physical, emotional, social or practical areas. This together makes the outpatient visit with the gastroenterologist more efficient and patient centered and guarantees that all relevant topics will be discussed and patients will be referred to other specialists whenever necessary. In the MUMC+ we developed a precision medicine model for IBD management, in which care

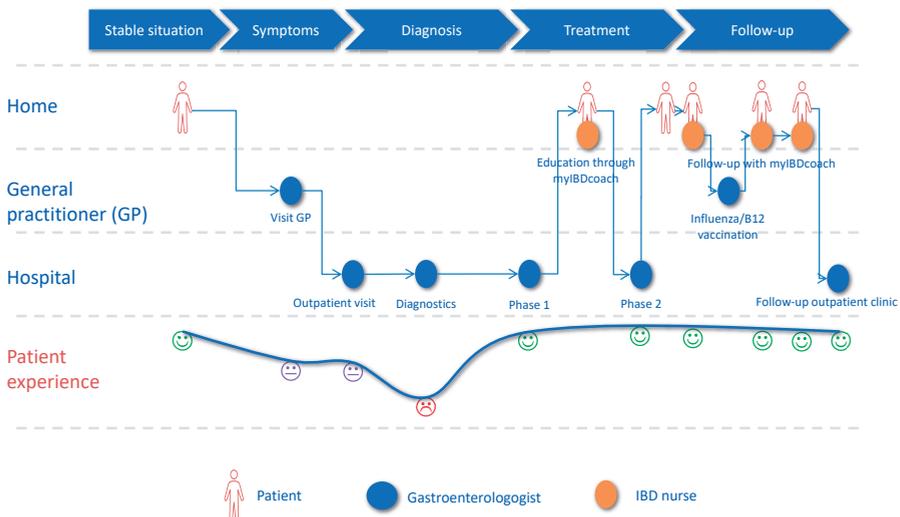
Gastroenterologist: MyIBDcoach monitors disease activity, but also all different aspects of this complex disease that matter to patients. Such a holistic approach results in more intensive consultations, but it also enriches my work. I believe that tight control and such a holistic approach will improve disease outcomes for IBD on the long-term.

pathways are reorganised with myIBDcoach towards value-based healthcare (see figure 1). After diagnosis, patients start using myIBDcoach and receive immediately adequate education. The follow-up exists of one yearly outpatient visit; in between patients will be telemonitored and mainly managed by specialised IBD-nurses. For each patient, PROMs and patient-reported experience measures (myIBDcoach), classical outcome measures, process indicators and costs (structured registration in hospital information system) are continuously registered and coded. These data are stored in a data-hub and processed to optimise patient-stratification and care pathways for these groups.

Standard care



myIBDcoach



Patient
 Gastroenterologist
 IBD nurse

Figure 1. Care pathways with and without myIBDcoach.

Value for society

In addition to more efficient organisation of IBD healthcare, better accessibility of care for IBD patients and a reduction in healthcare costs, this thesis also showed that telemedicine contributes to a reduction in indirect healthcare costs. Due to the early onset and chronicity, IBD profoundly affects work productivity with accompanying economic losses. In the myIBDcoach trial we asked patient to report their hours of sick leave from work and converted these hours into economic losses from a societal perspective, which was €1,886 for myIBDcoach users and €2,058 for patients receiving standard care. Using myIBDcoach, patients only have to visit the hospital when necessary; they can fill out questionnaires at any suitable moment and do not need to ask free from work. In addition, by lowering patients' disease burden and improving patient-empowerment, patients will probably experience less inconvenience of their disease in daily life and work.

In the Netherlands, where around 80,000 patients suffer from IBD, implementation of telemedicine with myIBDcoach would result in a yearly cost saving of 44 million Euro for society. Furthermore, by generating data on quality indicators, telemedicine with myIBDcoach enables benchmarking of IBD clinics and evaluation of practice variation towards better quality of care.

Value for research

MyIBDcoach enables structured registration of PROM data from large patient cohorts. These data can be used for research purposes. Furthermore, myIBDcoach, in combination with at home fecal calprotectin monitoring, is an excellent tool for treatment strategy trials. Currently, several trials are investigating whether de-escalation or episodic administration of biologicals is safe and whether risk factors for recurrence of disease after de-escalation can be identified. In patients who discontinue treatment, close monitoring of disease activity is warranted to enable timely intervention in case of a relapse.

Overall and future value

This thesis showed that telemedicine with myIBDcoach bridges the gap between healthcare workers' requests for tight disease monitoring and continuity of care in an overburdened outpatient setting, patients' demands for more involvement in disease management and more attention to physical, emotional and practical aspects of the disease, and better accessibility of IBD care due to more efficient use of resources. The common benefit for all stakeholders is that implementation of myIBDcoach resulted in better disease outcome with lower costs. These results were needed to help decision makers in estimating the value of telemedicine for IBD. Over the past years this project received much attention (inter)nationally by patients, gastroenterologists, nurses, pharmaceutical industry, governments and insurance companies. Also, people outside the

IBD field were interested. We were invited to present our research at large international congresses and on meetings of decision makers in the Netherlands. This resulted in research prizes, but also in a healthcare innovation award, nomination for the Dutch Value Based HealthCare prize, a nomination as Zinnige Zorg Initiative (Meaningfull Care Initiative) by the insurer VGZ, and the use of myIBDcoach as best practice example by the Federation of Dutch University Medical Centres (NFU)³, by the Dutch Healthcare Authority (NZA)⁴ and by the Dutch Patient Federation. At present, myIBDcoach is used in routine care in 17 hospitals throughout the Netherlands. The optimised myIBDcoach care pathways are shared within this network. Since myIBDcoach will be reimbursed from January 2019, we expect a further adoption of myIBDcoach in the Netherlands. Next, the National Health Service from the United Kingdom, and different hospitals around the world showed their interest in a translated version of myIBDcoach for use in their IBD clinic.

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'Minder opnamen van darmziekte-patiënten dankzij online begeleiding'

<https://www.nu.nl> 15 juli 2017 12:58

De e-health-toepassing MijnIBDcoach, die helpt bij de begeleiding van patiënten met een chronische inflammatoire darmaandoening (IBD) zoals Crohn, blijkt succesvol.

De toepassing zorgt ervoor dat het aantal ziekenhuisopnamen is gehalveerd, er minder polibezoeken plaatsvinden en dat er een betere therapietrouw is. Dat blijkt uit een onderzoek onder bijna duizend patiënten in verschillende Nederlandse ziekenhuizen, onder leiding van het Maastricht UMC+.

MijnIBDcoach laat de patiënt op een interactieve manier over zijn ziekte leren en laat hem of haar communiceren met zijn behandelaar. Die kan op zijn beurt de patiënt op afstand volgen en indien nodig actie ondernemen.

De helft van de onderzoekdeelnemers mocht de toepassing gebruiken. Uit het onderzoek (zaterdag gepubliceerd in het wetenschappelijke tijdschrift *The Lancet*) blijkt dat het aantal patiënten dat in het ziekenhuis opgenomen moest worden, met 50 procent is verlaagd in vergelijking met de groep die de toepassing niet gebruikte.

Wat betreft bezoeken aan de polikliniek is er een afname van 39 procent geconstateerd. Ook zijn patiënten die gebruik maken van de toepassing meer tevreden over de kwaliteit van zorg.

80.000 Nederlanders

Meer dan 80.000 Nederlanders hebben in Nederland last van een chronische darmziekte. De ziekte van Crohn en colitis ulcerosa zijn de twee voornaamste vormen van chronische ontstekingsziekten van de darm.

"Dit bewijst de meerwaarde en potentie van e-health toepassingen voor het efficiënter inrichten van de zorg", aldus maag-, darm-, leverarts Marieke Pierik.

"De tool levert dus een waardevolle bijdrage aan de zorg voor patiënten met een chronische darmaandoening. Willen we de kosten in de toekomst beheersbaar blijven houden, dan zijn structurele veranderingen in de zorg nodig. E-health toepassingen, zoals MijnIBDcoach, zijn uitermate geschikt om het primaire zorgproces efficiënter in te richten, zonder het belang en de behoeften van de patiënt uit het oog te verliezen."

