Introducing eHealth and other innovative options into clinical genetic patient care in view of increased efficiency and maintenance of quality of care
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Chapter 8

Summary
The aim of this research was to investigate promising innovations in clinical genetic patient care to find new and more effective ways of providing genetic counseling and information to our patients, while maintaining the quality of care. We aimed to determine patient outcomes and evaluations, and professionals’ opinions and evaluations, including cost aspects, on three types of innovations in our clinical genetic care: (1) group genetic counseling; (2) telegenetics application in general, and online genetic counseling specifically, and (3) the recontacting of former genetic patients. This chapter provides an overview of our main findings.

In Chapter 2 we described the results of a cohort study on group genetic counseling of cardiomyopathy index patients, as carried out in various regional hospitals in the northern part of the Netherlands. Counseling sessions consisted of a main plenary (informational) part, short individual discussions, and the possibility of giving blood for DNA testing. In total 13 group sessions were held in 8 regional hospitals, for 82 symptomatic cardiomyopathy patients and their partners/relatives. Patients reported they were overall satisfied and their questions had been answered. Their changes in perceived personal control and anxiety were comparable to previous reports of group genetic counseling and individual oncogenetic counseling. Regional cardiologists and heart failure nurses were also satisfied with this new approach, whereas the genetic professionals involved were less satisfied, mainly due to the large time investment on their part and the more limited than expected group interaction during the sessions. However, the reported patient outcomes showed that this could be an acceptable type of care from the patients’ perspective as an alternative care modality to individual genetic counseling at the University Medical Center. However, the optimal design of this new type of care, taking into account both patients’ and providers’ perspectives, still has to be determined. The composition of the counseling team, as well as the number of professionals involved in these group sessions may be reconsidered to reduce the professional’s total time investment.

Chapter 3 covered the economic analysis of our group genetic counseling design in regional hospitals, in terms of patient uptake, the percentage of counseled patients having their DNA tested, and the resultant quality of life effects (in terms of anxiety and perceived control) of our new approach. In addition, we compared our new group approach to conventional, individual counseling given in regular regional outpatient clinics and in the UMC, and to two alternative models of offering genetic counseling: group genetic counseling at the UMC and individual counseling at patients’ local hospitals. This analysis showed that our regional group counseling reached substantially more patients than had been referred to the UMC in previous years. Moreover, the total differences in costs of the various scenarios of group or individual cardiogenetic counseling were relatively small, although individual counseling given locally is the preferred scenario from the patients’ and societal perspective. From the provider’s perspective, group counseling should preferably be held at the UMC, but
it is unclear to what degree the hospital setting, and the travel time and cost would then impact the referral rate, and attendance rate of patients. Overall, group counseling as a care modality could be an appropriate addition to current clinical genetic care, but the composition of the team, location of the group sessions, and optimal group size may need some reconsideration.

Chapter 4 reported the results of an online survey amongst European genetic professionals on the current availability and use of various telemedicine applications among clinically working genetics professionals. The survey revealed three main points: telemedicine applications are only limitedly available and have an even more limited use throughout a substantial number of European countries, which could both be extended; each telemedicine application is being used for various activities; and cooperation, education and guidelines might be helpful in successfully increasing the use of telegenetics. Three main groups of barriers to its use were reported by respondents, most of whom did not have personal experience with using telemedicine: lack of perceived suitability and need, practical constraints, and lack of professional support/knowledge. These could be indications that the opportunities of telegenetics are so far largely unseen, and thus unused. We concluded that there is sufficient ground to extend the use of Telegenetics applications in Europe, both in direct and indirect patient care. To achieve this, the perceived practical and regulatory barriers should be overcome, and we need to raise awareness of the possibilities and likely advantages of telegenetics amongst genetics professionals.

Chapter 5 reported the results of a matched cohort study with pre- and post-measurements for online genetic counseling for cascade screening of cardiogenetic and oncogenetic patients, and for urgent prenatal counseling. Online counseling was given to patients in their own homes, at a relatively short distance from the hospital. Patients needed to undertake various preparations. Genetic counseling was given using a dedicated online platform with supportive tools that were available during counseling, in addition to a webcam image on screen. Patient outcomes on satisfaction, perceived personal control and anxiety showed that those involved in online genetic counseling were satisfied and the changes in their levels of perceived personal control and anxiety were, on average, similar to those of patients undergoing conventional, in-person counseling at the outpatient department. The patient evaluations showed that this self-prepared online care in patients’ homes is feasible, and that the main advantages for patients afterwards were the decreased time investment/travelling and having counseling in a familiar environment.

Chapter 6 reported the professionals’ perspective on online genetic counseling for presymptomatic testing of cardiogenetic and oncogenetic patients, and urgent prenatal counseling, and gave a cost and time analysis of this type of care. We performed a cohort study with pre- and post-measurements in ten genetic counselors, studying their
satisfaction with telemedicine, and the impact on cost and time of this type of counseling. Counselors considered our current online application to be qualitatively inadequate for use in regular care, mostly because of the technical characteristics and imperfections, and because of the relative lack of personal contact. On the positive side, online counseling allowed them to have more flexibility in work processes, to possibly avoid travelling time to regional hospitals, and allowed them to monitor cascade screening in families living all over the country. The time and cost analyses showed that less time and lower costs were involved in this new type of counseling than for conventional in-person counseling at the outpatient clinic. However, when we continue the use of the current external provider of the application upon its implementation in regular care, we will need additional investments in terms of licenses and technical support. Altogether, online counseling could reasonably be offered as an addition to the current spectrum of genetic care options to that group of our patients who have the required facilities and are open to use online options. However, technical imperfections mean that online counseling at this stage cannot be regarded as a full alternative to in-person counseling. Technical improvements and adaptations need to be made before this application will be considered sufficient by counselors for adopting on a larger scale in regular patient care.

Finally, Chapter 7 covered issues surrounding the duty to recontact former patients in clinical genetics. We performed a systematic review of 61 articles published up to 1 September 2014, and selected from 1428 hits in four different databases. Articles were included when they reported about the duty to recontact in clinical genetics, and the ethical, legal, social and practical aspects were discussed in the light of new genetic diagnostic technologies. Our review showed that most authors consider recontacting to be ethically desirable, but that they saw practical concerns as the main barriers. Various solutions to these barriers have been proposed in the literature, but so far there is little empirical evidence on recontacting in practice, for example reporting evaluations of preferred/feasible methods for recontacting, and patient opinions and outcomes of being recontacted. The available empirical studies show that most patients appreciated being recontacted for various indications and time spans since their counseling. We concluded that reaching a professional consensus and obtaining more empirical evidence – by performing pilot projects – on the specific situations in which recontacting is regarded as a good standard of care, and establishing guidelines are important next steps. The preferred method of recontacting, both from the patients’ and providers’ perspectives, should be determined, taking into account the psychological impact, the ethical and legal preconditions, the possibility of dynamic consent, and the feasibility and costs of a recontacting system, for example. Using an online tool to achieve some of these requirements could be a next step in the research into the introduction of recontacting practice in clinical genetics.