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TEACHING SERIES

How to initiate eHealth in congenital heart disease patients?

Mark J. Schuuring [1]* and Dirkjan Kauw[1,2]

[1]Department of Cardiology, Amsterdam UMC location AMC, University of Amsterdam, the Netherlands and [2]Netherlands Heart Institute, Moreelsepark 1, 3351 EP Utrecht, the Netherlands

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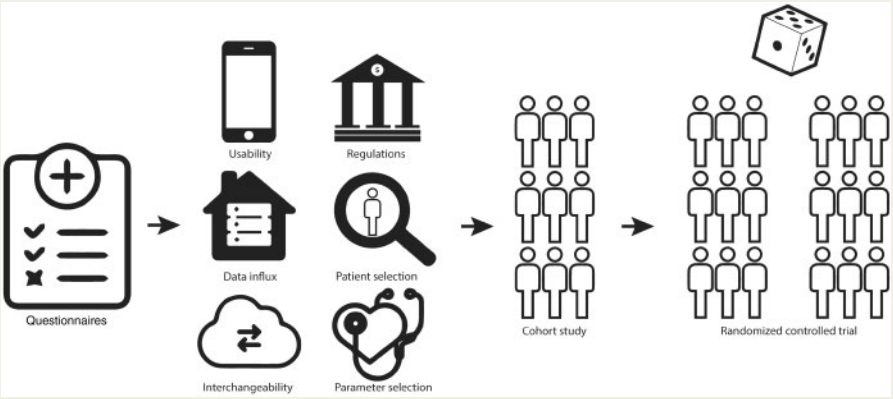
Patients with congenital heart disease (CHD) are a vulnerable subgroup of cardiac patients. These patients have a high morbidity and high mortality rate. As the number of patients with CHD keeps growing, while also getting older, new tools for the care and follow-up of these vulnerable patients are warranted. eHealth has an enormous potential to revolutionize health care, and particularly for CHD patients, by expanding care beyond hospital walls and even moving some of the provided care to the comfort of home. As new eHealth tools continue to grow in number, such as invasive eHealth tools, health care delivered through eHealth continues to evolve. This teaching series summarizes current insights and discusses challenges yet to be overcome. Importantly, none of them are insurmountable. This all lays ground for a promising future for eHealth in the care of patients with CHD.

Graphical Abstract



Keywords Telemedicine • Heart disease • eHealth • Congenital heart disease • ACHD

* Corresponding author. Tel: +31 (0) 205669111, Email: m.j.schuuring@amsterdamumc.nl

Introduction

eHealth is rapidly developing and innovative technical applications and solutions continue to grow in number. Some highly anticipated technologies, such as remote monitoring of patients with acquired heart failure or arrhythmias, have initially shown disappointing results in large randomized controlled trials in terms of reducing mortality and hospitalizations.[1] However, recently a large randomized controlled trial on telemonitoring in patients with acquired heart failure demonstrated a reduction of mortality in highly selected patients.[2] These patients were being monitored at home 24 h a day, 7 days a week, resulting in an intensive and costly telemonitoring programme. Nonetheless, these positive results indicate that eHealth is gradually evolving and learning from its past mistakes.

Patients with congenital heart disease (CHD) are a vulnerable subgroup of cardiac patients. These patients have a high morbidity and high mortality rate. As the number of patients with CHD keeps growing, while also getting older, new tools for the care and follow-up of these vulnerable patients are warranted.

Until recently, limited data were available on the effects of eHealth on clinical outcomes in CHD patients. This Teaching is a brief update on current applications and future perspectives of eHealth in the care of adult patients with CHD. We describe advantages and challenges of eHealth in CHD patients and identified patients with a high risk for clinical deterioration, who might benefit most from using eHealth. The relatively young adult CHD population only rarely uses mHealth, but the majority demonstrated in questionnaires to be motivated to start using eHealth, see *Figure 1*.[3] Particularly the adult CHD population is a highly attractive patient group in which to initiate mHealth initiatives due to their relatively young age, affinity with mobile devices, chronic condition necessitating lifelong surveillance, and the general need to reduce the burden of disease.[3] In a questionnaire study with a median age of 40 (range 18–78) years, 92% owned a smartphone.[3] In a similar study by Lopez *et al.*[4] among adolescents (between 16 and 20 years of age) and adults (21–40 years of age) with moderate or complex CHD, all had access to the Internet via a mobile phone, and 55% had searched online for information on CHD.

Current insights

Kauw *et al.*[5] reviewed the medical literature and showed that only limited data were available on the use of eHealth applications in CHD patients. Most studies focused on paediatric patients. The most frequently used application of eHealth in CHD patients was home-monitoring of body weight and oxygen saturation in infants in between corrective surgery, which showed positive results in reducing mortality rate, complications, and improving nutritional status. These results demonstrated that using eHealth applications in CHD patients seems promising and should be further explored.

One of the first steps to develop and implement a new technique such as eHealth is a stakeholder analysis, see *Figure 1*. In the Netherlands, a dedicated stakeholder analysis was performed to evaluate experiences of users of eHealth telemonitoring programmes to identify the challenges that have to be overcome to improve success rates of future eHealth programmes in adult CHD patients.[6] Semi-structured interviews were conducted with cardiologists, nurses, patients, health care managers, and Information Communication Technology (ICT)-developers in order to identify the main hurdles of these programmes. Interestingly, different challenges were experienced in the various subgroups, indicating that collaboration between all involved parties is essential for a successful integration of an eHealth programme.

The next logical step in the evaluation of eHealth care in adults with CHD is an observational cohort study, see *Figure 1*. We performed a clinical cohort study in which adult CHD patients were enrolled in an eHealth programme.[7] Adult CHD patients were eligible for inclusion if they met the inclusion criteria: Palpitations within the last 3 years (with or without arrhythmia diagnosis) or heart failure (HF) New York Heart Association (NYHA) class ≥ II, and possession of a mobile device. Symptomatic patients were included, as the most

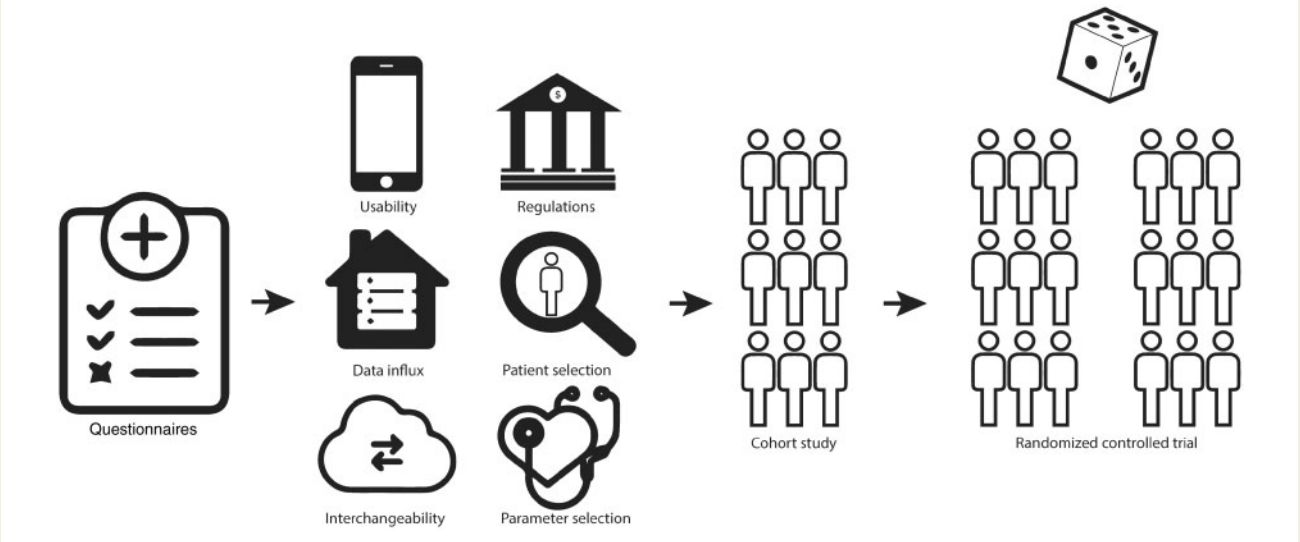


Figure 1 Graphical abstract on how to initiate eHealth in congenital heart disease patients?

benefit could be expected within this patient group. It is unclear what the effects of screening are in asymptomatic patients. This programme included weekly monitoring body weight, blood pressure, and heart rhythm. In this study, we demonstrated several clinical advantages of the eHealth programme, as we established new diagnoses of arrhythmias and hypertension, and medication adjustments were required in between outpatient clinic visits. Importantly, adherence was >70% in 77% of the patients that started weekly measurements (70/91). Patients that were female, older of age, and experienced palpitations at inclusion were more likely to acquire an adherence of >70%. These results are much better than adherence reported by Klausen *et al.*[8] Of 81 patients in an eHealth intervention group (mean age 14.6 years), only 8 (10%) were active users during the last week of the intervention. The Dutch programme did not find any differences in clinical outcomes with respect to hospital admissions, emergency hospital visits, and telephone contacts. As this cohort study used historical data, these results have to be interpreted with caution. Therefore, randomized controlled trials are required to further elucidate the effect of eHealth programmes on clinical outcomes in CHD patients, see *Figure 1*.

Discussion

For eHealth to be effective in the care of CHD patients, a few challenges still remain, such as usability of an eHealth tool, analysis of patient-generated data, interchangeability of data between different electronic medical records (EMR), adaptation of legal and financial regulations, identification of patients that will benefit most, and identification of parameters that are most indicative for the detection of clinical deterioration.

Firstly, using an eHealth device or application has to be straightforward for patients, as well as health care professionals. This challenge emerged from our stakeholder analysis, but is also demonstrated by other studies, especially in older patients.[9,10] A possible solution to this problem could be the automated collection of patient data (e.g. heart rate frequency monitoring by a smartwatch), which never misses a measurement if set-up correctly and happens unnoticed by the patient. This way challenges such as usability, but also patient adherence and medicalization of the patient can be overcome. Potentially, reminders or serious gaming affects adherence.[11] Examples of devices that automatically and unnoticed gather patient data are wearables or implantable devices, such as smartwatches or an implantable pulmonary artery pressure monitor device.[12]

Secondly, for health care professionals, the huge influx of patient-generated data is feared because this is thought to generate more workload, as all patient-generated data has to be analysed by physicians or nurses to prevent missing clinically significant information.[13] To automate the analysis of patient-generated data, machine learning techniques are currently being studied. These techniques are not yet used on a large scale in clinical practice, but it can be expected that these new techniques will provide accurate analysis of data and will reliably take over more and more of the workload of health care professionals.[14]

Thirdly, an important challenge for health care professionals, but also for ICT-developers, is the interchangeability of (patient-generated) data between different EMR systems.[15] Currently, in many countries, it is not yet possible to exchange data of the same patient between different EMR systems. In daily clinical practice, this is experienced as a major limitation. Therefore, for eHealth to be a success, adequate implementation in all different EMR systems and interchangeability of data between these systems is essential.

Fourthly, adapting financial and legal regulations to the use of eHealth in daily practice remains a challenge. Reimbursement of these new-developed forms of care, delivered through remote monitoring, was a pressing issue when the first eHealth programmes started and reimbursement by health care insurances only gradually took shape in the Netherlands. This hindered innovative eHealth programmes initially, however, health insurance companies and governmental regulations are now quickly adapting. Another issue in adapting regulations to eHealth is the legal side of this new concept of healthcare. For example, privacy of patient-generated data has to be guaranteed and liability in case of adverse events has to be regulated by law. Adequate legal and reimbursement regulations have to be continuously updated to keep up with recent technical innovations and to prevent a delay between innovation of healthcare and actually using it in daily clinical practice.

Fifthly, and probably one of the most important issues, is that the appropriate and most eligible patient groups have to be identified for the use of specific eHealth applications. Just applying eHealth to the whole CHD patient population is expected to not be effective, as severity of diagnosis and clinical status can differ greatly between patients. This has also been demonstrated in patients with acquired heart disease in patients with HF. Adequate patient selection is required to significantly improve the effectiveness and success of eHealth applications. We opted for symptomatic patients, because this is where the most benefits could be expected. However, this is subject of debate. A substantial number of CHD are associated with other features, including mental retardation.[16] Most studies excluded patients with mental retardation, because the effect of eHealth is uncertain in this group.

Finally, similar to eligible patient identification, identifying the most adequate and effective parameters to monitor in patients and detect early signs of deterioration is of great importance for the success of eHealth. Multiple studies have, for example, studied monitoring weight in acquired HF patients in order to detect deterioration, but with limited rates of success.[2,17]

Future expectations

New ways of monitoring patients with HF at home have emerged, such as invasive monitoring of the pulmonary artery pressure through an implemented device in the pulmonary artery.[18] Also home testing of B-type natriuretic peptide has been studied to predict HF decompensation.[19] These new parameters seem promising as they are believed to be more accurate in predicting HF decompensation than weight gain, however, large randomized trials still need to confirm this. As technical innovation increases the number of possible parameters to monitor, evaluation of these parameters should continue, not only for HF, but also for other (cardiac) diseases.

Conclusion

eHealth has an enormous potential to revolutionize health care, and particularly for CHD patients, by expanding care beyond hospital walls and even moving some of the provided care to the comfort of home. As new eHealth tools continue to grow in number, such as invasive eHealth tools, health care delivered through eHealth continues to evolve. Some of the discussed challenges have yet to be overcome, however, none of them are insurmountable. This all lays ground for a promising future for eHealth in the care of patients with CHD.

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Data availability

No new data were generated or analysed in support of this research

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