eHealth in adults with congenital heart disease

Current and future perspectives

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GENERAL DISCUSSION: CARE FOR ADULT PATIENTS WITH CONGENITAL HEART DISEASE: FUTURE PERSPECTIVES

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FUTURE PERSPECTIVES

eHealth is rapidly developing and innovative technical interventions and solutions continue to grow in number. Some highly anticipated techniques, 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] Recently, a large randomized controlled trial on telemonitoring in patients with acquired heart failure demonstrated a reduction of mortality in highly selected patients.[2] However, these patients were being monitored at home 24 hours a day, seven days a week, resulting in an intensive and costly telemonitoring program. Nonetheless, these positive results indicate that eHealth is gradually evolving and learning from its past mistakes. However, for adults with congenital heart disease (ACHD), a vulnerable subgroup of cardiac patients, limited data is available on the effects of eHealth on clinical outcomes. As the number of ACHD patients keeps growing, while also getting older, new tools for the care and follow-up of these vulnerable patients are warranted. For eHealth to be effective in the care of ACHD 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 should be monitored for 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 qualitative study, but is also demonstrated by other studies, especially in older patients.[3,4] 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. 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.[5,6]

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 analyzed by physicians or nurses to prevent missing clinically significant information.[7] To automate the analysis of patient-generated data, machine learning techniques are currently being studied. These techniques are not yet being 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.[8]

Another important challenge for health care professionals, but also for ICT-developers, is the interchangeability of (patient-generated) data between different EMR systems.[9] Currently, in the Netherlands, 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.

Furthermore, adapting financial and legal regulations to the use of eHealth in daily practice remains a challenge. Reimbursement of this new-developed form of care, delivered through remote monitoring, was a pressing issue when the first eHealth programs started and reimbursement by health care insurances only gradually took shape in the Netherlands. This hindered innovative eHealth programs 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.

Lastly, 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 ACHD patient population is not 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 heart failure.[10,11] Adequate patient selection is required to significantly improve the effectiveness and success of eHealth applications.

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 heart failure patients in order to detect deterioration, but with limited rates of success.[2,10] New ways of monitoring patients with heart failure have emerged, such as invasive monitoring of the pulmonary artery pressure through an implemented device in the pulmonary artery.[12] Also home testing of B-type natriuretic peptide (BNP) has been studied to predict heart failure decompensation.[13,14] These new parameters seem promising as they are believed to be more accurate in predicting heart failure 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 heart failure, but also for other (cardiac) diseases.

eHealth has an enormous potential to revolutionize health care for ACHD 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 ACHD patients.

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