Taylor & Francis
Taylor & Francis Group

Expert Review of Cardiovascular Therapy

ISSN: 1477-9072 (Print) 1744-8344 (Online) Journal homepage: https://www.tandfonline.com/loi/ierk20

eHealth in patients with congenital heart disease: a review

Dirkjan Kauw, M.A.C. Koole, Jolien R. van Dorth, Igor I. Tulevski, G. Aernout Somsen, Marlies P. Schijven, Daan A.J. Dohmen, Berto J. Bouma, Barbara J.M. Mulder, Mark J. Schuuring & Michiel M. Winter

To cite this article: Dirkjan Kauw, M.A.C. Koole, Jolien R. van Dorth, Igor I. Tulevski, G. Aernout Somsen, Marlies P. Schijven, Daan A.J. Dohmen, Berto J. Bouma, Barbara J.M. Mulder, Mark J. Schuuring & Michiel M. Winter (2018) eHealth in patients with congenital heart disease: a review, Expert Review of Cardiovascular Therapy, 16:9, 627-634, DOI: 10.1080/14779072.2018.1508343

To link to this article: https://doi.org/10.1080/14779072.2018.1508343

Published online: 20 Aug 2018.

EXPERT REVIEW OF CARDIOVASCULAR THERAPY
2018, VOL. 16, NO. 9, 627–634
https://doi.org/10.1080/14779072.2018.1508343

REVIEW

eHealth in patients with congenital heart disease: a review

Dirkjan Kauw*[a,b], M.A.C. Koole*[a,c,d], Jolien R. van Dorth[a], Igor I. Tulevski[d], G. Aernout Somsen[d], Marlies P. Schijven[e], Daan A.J. Dohmen[f], Berto J. Bouma[a], Barbara J.M. Mulder[a], Mark J. Schuuring[a,g] and Michiel M. Winter[a,d]

[a]Department of Cardiology, Amsterdam UMC, University of Amsterdam, Amsterdam, the Netherlands; [b]Netherlands Heart Institute, Utrecht, the Netherlands; [c]Department of Cardiology, Red Cross Hospital, Beverwijk, the Netherlands; [d]Cardiology Centers of the Netherlands, Amsterdam, the Netherlands; [e]Department of Surgery, Amsterdam UMC, University of Amsterdam, Amsterdam, the Netherlands; [f]FocusCura, Driebergen-Rijsenburg, the Netherlands; [g]Department of Cardiology, Haga Teaching Hospital, The Hague, the Netherlands

ABSTRACT

Introduction: Mobile health (mHealth), an advanced form of eHealth is expected to drastically change the field of traditional healthcare in the near future as wearables and mobile applications are rapidly increasing in number. The majority of patients with congenital heart disease (CHD) now reach adulthood and this relative young patient population seems particularly suited for mHealth, as they require lifelong follow-up, experience high morbidity burden, and were raised in this digital era. In patients with acquired heart disease the potential of eHealth has been demonstrated, yet data are still inconclusive.
Areas covered: In this review of the current literature we evaluated the effect of various eHealth interventions in patients with CHD. Our search resulted in a mere 10 studies, which comprised mostly of children or adolescents with severe CHD. Home-monitoring of saturation and weight through mHealth was found to be beneficial in patients after palliation procedures, and video conferencing was found to have a positive effect on anxiety and healthcare utilization.
Expert commentary: Due to high morbidity and mortality in patients with CHD and the promising results of eHealth interventions, further research is desperately needed.

ARTICLE HISTORY
Received 26 April 2018
Accepted 2 August 2018

KEYWORDS
Congenital heart disease; eHealth; mHealth; telemonitoring; mobile health

1. Introduction

Mobile health (mHealth), an advanced form of eHealth and a provision of targeted medical care through mobile technologies, is expected to drastically change traditional healthcare structures and is reputed to be cost-effective and even cost-saving. The growing congenital heart disease (CHD) population seems especially prone to benefit from mHealth, as they are young, familiar with digital applications, and require lifetime follow-up.

Thanks to the progress in cardiothoracic surgery, and medical therapy the large majority of CHD patients now reach adulthood. The estimated number of CHD patients currently is around 3000 per million adults and the total population with CHD is estimated to be 2.4 million in the United States of America [1–4]. Considering this increasing number of CHD patients worldwide, an intervention that improves health-related quality of life (HR-QOL), reduces adverse events, and decreases the number of hospital visits, will have positive, and long-term effects on patients' wellbeing, clinical outcome, and overall healthcare costs. In theory, mHealth could provide such an intervention.

In patients with acquired heart disease, several studies have demonstrated the potential benefits from eHealth. In patients with paroxysmal atrial fibrillation, telemonitoring through mHealth provided rapid out-of-hospital diagnoses of recurrence of atrial fibrillation and the possibility to instruct patients and manage the episode, without necessitating a visit to the hospital [5]. Also the use of smartwatches has been studied to detect atrial fibrillation with a certain extent of success [6]. Patients with uncontrolled hypertension showed better outcome when their blood pressure was monitored using telemonitoring with provision of telephone support, compared to a control group [7]. A recent systemic review on mHealth in patients with congestive heart failure demonstrated that a variety of mHealth solutions reduced morbidity, with a trend to decreased mortality and hospital admissions. Total costs, however, increased due to the implementation of new technologies [8]. A recent systematic review on the economic impact of mHealth in non-CHD patients describes positive reports on cost outcome of mHealth [9]. So far, however, results of studies on telemonitoring in acquired heart disease are conflicting [10].

The advantages of mHealth seem to hold specifically true for CHD patients, requiring lifelong follow-up at the outpatient clinic. Symptoms, such as cardiac arrhythmias and heart failure, often result in visits to the emergency department, hospitalization, or premature death. Currently, CHD patients are mostly dependent on planned visits to their cardiologists. Visits to the outpatient clinic are set at predefined times, irrespective of symptomatology or patients' needs. Indeed, in patients with acquired heart disease, such as congestive heart

CONTACT Michiel M. Winter m.m.winter@amc.uva.nl Department of Cardiology, Amsterdam UMC, University of Amsterdam, Meibergdreef 9, 1105 AZ Amsterdam, the Netherlands

*Both authors contributed equally to this work.

failure, there is hardly any correlation between outpatient visits and the occurrence of symptoms [11]. Midterm evaluation and accessible communication with the physician remain difficult. mHealth seems the perfect solution to provide routine care for CHD patients, as it provides the possibility to monitor, diagnose, and treat patients at their request, in between visits to their health care professional, or at the earliest signs of deterioration in order to prevent emergency hospitalizations. mHealth has the potential to put the patient into the lead and is expected to increase HR-QOL and decrease cardiac morbidity and (unnecessary) visits to the hospital.

Despite the fact that mHealth could be extremely useful in the follow-up of CHD patients, and suitable mHealth applications seem numerous, the effect of mHealth on patients with CHD remains unknown. We conducted this review of the current literature with the primary objective to evaluate the current use of mHealth and its effect in patients with CHD.

2. Methods

2.1. Literature search

Relevant studies were found by searching the PubMed database. Search terms regarding CHD were combined with search terms regarding adult patients and eHealth. The full search strategy used for our PubMed search can be found in Box 1. The last search on PubMed was performed on 1 January 2018. The search was not restricted to publication date or article type. However, studies that were not available in full text or were written in a language other than English were excluded.

Box 1. PubMed search strategy.

('Heart Defects, Congenital'[Mesh] OR congenital heart defect*[tiab] OR congenital heart diseas*[tiab] OR cardiac abnormalit*[tiab] OR ((heart [tiab] OR cardiac[tiab] OR cardial*[tiab] OR cardiol*[tiab] OR mitral* [tiab] OR aorti*[tiab] OR aorta*[tiab] OR pulmon*[tiab] OR tricuspid* [tiab] OR valv*[tiab]) AND (malform*[tiab] OR anomal*[tiab])) OR ((CHD [tiab] OR CHDs[tiab]) AND congenit*[tiab]) OR cyanot*[tiab] OR coarct* [tiab] OR Ebstein*[tiab] OR (tricuspid[tiab] AND (atresi*[tiab] OR malform*[tiab])) OR ((septal[tiab] OR septum[tiab]) AND defect*[tiab]) OR VSD[tiab] OR ((atrioventric*[tiab] OR atrio-ventr*[tiab] OR AV[tiab]) AND defect*[tiab]) OR Eisenmenger*[tiab] OR Fallot*[tiab] OR (double outlet*[tiab] AND ventric*[tiab]) OR (transposit*[tiab] AND great[tiab] AND (arterie*[tiab] OR artery*[tiab] OR vessel*[tiab])) OR ((dextr*[tiab] OR TGA[tiab]) AND transposit*[tiab]) OR CCTGA*[tiab] OR (Mustard* [tiab] AND (operation*[tiab] OR surg*[tiab] OR repair*[tiab] OR patient [tiab] OR patients[tiab] OR procedur*[tiab])) OR Senning*[tiab] OR Jatene*[tiab] OR ((arteria*[tiab] OR arterie*[tiab] OR artery*[tiab]) AND switch*[tiab] OR univentricular*[tiab] OR cavo-pulmonar*[tiab] OR cavopulmonar*[tiab] OR Blalock*[tiab] OR Fontan*[tiab] OR Taussig* [tiab] OR Norwood*[tiab] OR ((pulmon*[tiab] AND (stenos*[tiab] OR atres*[tiab])) OR (bicuspid*[tiab] AND (aorti*[tiab] OR aorta*[tiab])) OR ((RV[tiab] OR right ventric*[tiab] OR LV[tiab] OR left ventric*[tiab]) AND (outflow[tiab] OR tract[tiab]) AND obstruct*[tiab]))
AND
('Telemedicine'[MeSH] OR telemedicine[tiab] OR mobile health[tiab] OR electronic health[tiab] OR mHealth[tiab] OR telehealth[tiab] OR eHealth [tiab] OR m-health[tiab] OR e-health[tiab] OR home-monitor*[tiab] OR telecardiolog*[tiab] OR teleconsult*[tiab] OR telemonitor*[tiab] OR mobile technolog*[tiab] OR internet*[tiab] OR web[tiab] OR SMS[tiab] OR short message service[tiab] OR ambulatory monitor*[tiab] OR outpatient monitor*[tiab] OR remote monitor*[tiab] OR digital health [tiab] OR mobile telephon*[tiab] OR mobile phon*[tiab] OR cell phon* [tiab] OR cellular phon*[tiab] OR cellular telephon*[tiab] OR smartphon*[tiab] OR smart phon*[tiab] OR wearable*[tiab] OR mobile devic*[tiab] OR mobile app*[tiab])

2.2. Study selection

Studies were considered for inclusion if they fulfilled the following inclusion criteria: the presence of CHD in any form; an intervention was performed through some form of eHealth, outcomes had to comprise the effect of the eHealth intervention. Studies that used a passive form of eHealth, such as consistent home-monitoring through pacemakers and/or implantable cardioverter defibrillators, were excluded as we did not deem this a form of eHealth used by the patient. Case reports and reviews were also excluded from our study.

2.3. Data extraction

Data were extracted from the studies that met our inclusion criteria. The following information was extracted from the articles: first author, publication year, study design, type of CHD of the patient population, number of included patients, baseline characteristics, type of eHealth intervention, measured outcomes, and the follow-up duration. Furthermore, we noted the differences in (cardiac) morbidity and mortality, changes in weight and (un) planned interventions, and other relevant outcomes.

3. Results

3.1. Search results

Our PubMed search yielded a total of 227 records. Thirteen additional records were identified through reference screening (JD). As a result, 240 records were screened for duplicates, one duplicate was found, after which 239 records were screened on title and abstract (JD). When in doubt, a second reviewer was consulted (MW). 194 studies were considered irrelevant, and the residual 45 studies were screened on full text using the inclusion- and exclusion-criteria described in the Methods section. Thirty-five of those studies were excluded because of the chosen intervention not being eligible (n = 27), study design (n = 4), selected outcome measures (n = 2), included patient population (n = 1), and one study described preliminary data of the same study. Eventually, 10 studies fulfilled the inclusion criteria and were included in the review. See Figure 1.

Included studies were published between 2004 and 2017, and consisted of 994 CHD patients. The largest study included 230 participants, and the smallest study included 24 participants. Four studies were retrospective studies, two were observational studies, three were randomized controlled trials, and one cross sectional study. Study characteristics can be found in Table 1.

3.2. Patient population

In total, 994 patients were included in our review, of which 569 patients were included in an intervention group, and 425 in a control group. The majority of the included patients were infants. There was a large variety of CHD type, consisting of patients with simple, moderate, and complex lesions, such as

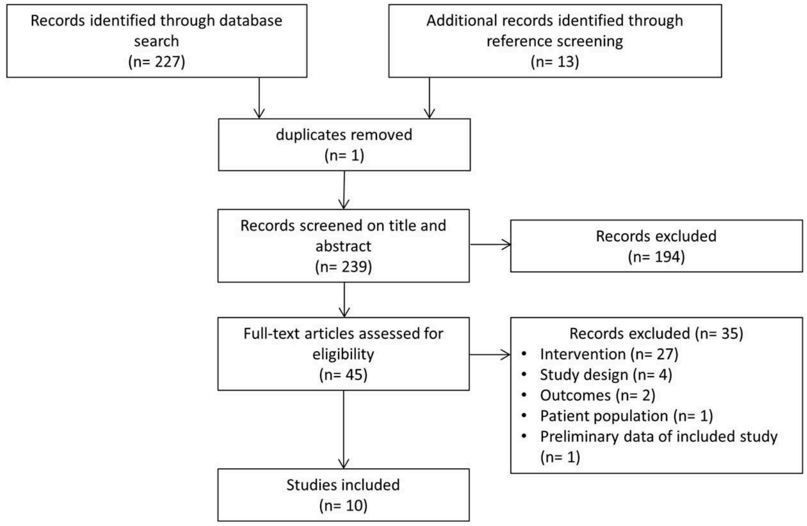

Figure 1. Flowchart of included studies.

Tetralogy of Fallot and hypoplastic left heart syndrome (HLHS). The majority of studies included patients with a single ventricle circulation.

3.3. Interventions

Five types of eHealth interventions were described. Home-monitoring of vital parameters, such as heart rate, nutritional intake, weight, and oxygen saturation, was the most frequently evaluated intervention, used by five of our included studies [12–16]. Also video conferencing, the current needs for disease specific information in preparation for the development of an online information portal, texting with teens with CHD and eHealth encouragements through internet, texts or mobile applications were described [4, 17–20]. The results of the studies are shown in Table 2.

3.3.1. Home-monitoring

Several studies performed home-monitoring in between two types of corrective surgery, as survival after stage one surgical palliation remains high and with the aim to improve outcome and mortality in the interstage period. Ghanayem et al. [13] were the first to describe home-monitoring in infants after palliation for HLHS. They performed daily home-monitoring of body weight and oxygen saturation to identify the risk of interstage death. Several years later, Petit, Siehr, and Harahsheh et al. [14–16] performed similar studies and monitored nutritional intake, weight gain, and oxygen saturation in a similar patient population. Castellanos et al. [12], Ghanayem et al. [13], and Siehr et al. [16] found improved interstage mortality in infants after palliation. A reduction of complications after stage two palliation was found by Harahsheh et al. [14]. Ghanayem et al., Harahsheh et al., and Petit et al. [13–15] found a reduced age at stage two palliation. Also nutritional status surveillance improved weight at stage two palliation, Petit et al. [15] and Harahsheh et al. [14] found a significant improvement in interstage weight gain.

3.3.2. Online disease specific information portal

One study evaluated the current needs and preferences for disease-specific evidence-based information in the Netherlands in response to an increased demand for patient information on CHD. Since congenital heart defects can be complex and diverse, patients often require disease specific information. Through interviews and comprehensive surveys the current state of patient information was evaluated, in preparation of the development of online, disease- and age-specific information portal. The online portal is currently being developed and its effect on patients and caregivers is currently being assessed [4]. Results of questionnaires and interviews indicated that patient/caregiver disease-specific knowledge is limited and numeracy was limited. According to the respondents, 38% lacked information that was reliable and available and thus a reliable and accessible source of information was needed.

3.3.3. Video conference

Two studies assessed the feasibility and advantages of home-monitoring of infants with major CHD by videoconference as this could provide additional information to the cardiologist and since tele-home care has already become established as a useful support mechanism for adults with other specific chronic illnesses [21–23]. McCrossan et al. [17] evaluated the impact on healthcare resource use and healthcare costs by using video conferencing and Morgan et al. [18] aimed to decrease anxiety and to clinically monitor patients by using video conference versus telephone contact. McCrossan et al. [17] found that home support using video conferencing reduced healthcare resource use significantly with a mean of 7.7 health service utilizations in 10 weeks in the video conference group versus 13.3 in the telephone group and 12.9 in the control group, also in 97% of the video conferences the clinician felt that the concerns of the parents could be

Table 1. Summary of included studies.

Author	Year	Study design	Patient population	*n* (total)	*n* (intervention)	Intervention group	Control group	Outcomes	Follow-up duration
Home-monitoring(weight, pulse oximetry)									
Ghanayem et al.	2004	Retrospective	Children with HLHS	97	39	Daily pulse oximetry, daily weight.	58	Interstage survival	Time to S2P
Petit et al.	2011	Retrospective	Children with single ventricle heart defect	230	93	Daily pulse oximetry, daily weight, weekly phone calls with NP.	137	Interstage mortality, In hospital death after S1P, death or transplant at 1 year.	Time to first outpatient visit after S2P discharge
Harahsheh et al.	2016	Retrospective	Children with single ventricle heart defect	98	56	Pulse oximetry, weight records, and nutritional intake at least three times a week.	42	Interstage mortality, weight, weight-for-age z score, weight at stage two, frequency of post stage two complications	Time to discharge from S2P
Castellanos et al.	2016	Retrospective	Children with single ventricle heart defect	126	52	Pulse oximetry thrice a day, daily weight, weekly phone calls with NP.	74	Interstage mortality, interstage readmission, planned and unplanned reinterventions.	Time to S2P
Siehr et al.	2014	Prospective	Children with single ventricle heart defect	46	46	Daily pulse oximetry, heart rate, weight, and feedings. Weekly phone calls with NP.	NA	Interstage survival, number of readmissions, number of interventions.	Time to S2P
Video conferencing									
Morgan et al.	2008	RCT	Children <3 years, with severe CHD, admitted for palliation or surgical correction of known significant defect	27	14	Videoconferencing sessions twice a week.	13	difference in anxiety levels change in anxiety levels, parents opinion of video conferencing	6 weeks
McCrossan et al.	2012	RCT	Infants with major CHD	83	35 (video conference) 24 (telephone support)	Videoconferencing sessions once or twice a week. Parallel program for telephone support.	24	Healthcare resource use, clinicians' opinions on utility and quality of interventions, parental opinions on quality of interventions.	10 weeks
Text messaging									
Rempel et al.	2014	Prospective	Children with moderate or complex heart disease aged 15–17 years	24	24	Creation of a MyHealth passport, SMS contact with intervention nurse.	NA	Preference to be contacted via text message, effectiveness of texting, nature of texting interaction, risks and benefits of texting.	Duration of SMS conversation
eHealth encouragement for physical activity									
Klausen et al.	2016	RCT	Patients after repaired complex CHD between 13 and 16 years old under life-long follow-up	158	81	45 min group health education, 15 min individual counseling, 52-week Internet, mobile application, and SMS-based program	77	VO2 peak, physical activity, health-related quality of life.	52 weeks
Development of online information portal									
Etnel et al.	2017	Cross sectional	Patients with congenital aortic and/or pulmonary valve disease and/or Tetralogy of Fallot	105	105	Surveys and interviews	NA	current state of patient/caregiver knowledge, numeracy, involvement, patient information preferences and needs for online information portal	NA

HLHS: Hypoplastic Left Heart Syndrome; S2P: Stage 2 Palliation; NP: nurse practitioner; S1P: Stage 1 Palliation; NA: not applicable; RCT: randomized controlled trial; CHD: congenital heart disease.

Table 2. Summary of results of included studies.

Author (year)	Results
Home-monitoring(weight, pulse oximetry)	
	Monitoring vs. no monitoring
Ghanayem et al. (2004)	Interstage survival: 100% vs. 84,5% (P = 0.02)
Petit et al. (2011)	Interstage mortality: 8.3% vs. 12.1% (P = 0.924) In hospital death after S1P: 4.5% vs. 15.3% (P = 0.021) 1-year survival: 83.8% vs. 70.8% (P = 0.002)
Harahsheh et al. (2016)	Interstage mortality: 5.4% vs. 2.4% (P = 0.71), Weight-for-age z scores: Higher (−1.5 ± 0.97 vs. −1.58 ± 1.34, b = 0.30, P = 0.02) Stage II weight-for-age z score below −2: Lower likelihood for a (26.5 vs. 31.7%, OR 0.19, P = 0.03) Weight at stage two: Trend for higher weight (6.14 ± 0.82 vs. 6.05 ± 0.97, b = 0.25, P = 0.06) Complications post stage two: Lower likelihood(18.4 vs. 34.1%, OR 0.16, P = 0.02)
Castellanos et al. (2016)	Interstage mortality: 3.8% vs. 18.9% (P = < 0.001) Interstage mortality absolute reduction: 15% Unplanned readmission: 35% increase (P < 0.05) Major interventions: 17% of all readmissions
	Monitoring only
Siehr et al. (2014)	Interstage survival: 100% Readmissions: 19 patients (41%) had 27 readmissions Interventions: 17 major/minor interventions, 8 major interventions, 9 minor interventions
Video-conferencing	
	Videoconference vs. telephone only vs. control group
Morgan et al. (2008)	Parental attitude: VC 26.9% more beneficial (95% CI: 12.9–40.9%, P < 0.0001) Baseline anxiety: no significant difference Decrease in anxiety levels and positive change in anxiety levels(P < 0.05)
McCrossan et al. (2012)	Healthcare resource use: mean of 7.7 vs. 13.3 vs. 12.9 per 10 weeks (P < 0.001) Hospitalization rate: mean of 0 vs 0 vs 0, 5 admission per patient per 10 weeks (P = 0.006) Clinicians more confident making medical decisions (P = 0.01). Parents more satisfied (P = 0.001)
Text-messaging	
Rempel et al. (2014)	67% of teens used text messaging Contact established: 81% Benefits: flexibility, ability to respond overtime, information presented in bite-sized amounts, relevant answers to patient question. Risks: interaction may not be in depth, distraction, invasiveness.
eHealth encouragement for physical activity	
	eHealth encouragement vs. control
Klausen et al. (2016)	VO2 peak: 43.2 vs. 46.3 ml O2· kg−1· min−1 (P = 0.52). Physical activity per day: mean 40.3 (SD 21.8) vs. 41.3 (SD 22.9) min/day, not significantly different. Health-related quality of life, generic: 0.32; 95% CI −2.39 to 3.14, not significantly different. Health-related quality of life, disease specific: −0.72, 95% CI −3.73 to 2.89, not significantly different.
Development of online portal	
Etnel et al. (2017)	Patient/caregiver knowledge and numeracy: limited. Physicians inform patients selectively, patient involvement is sub-optimal. Disease-specific information: to 38% of patients not available

S1P: stage 1 palliation; OR: odds ratio; VC: videoconference.

properly addressed versus 64% in the telephone group. Parents were also more content after using video conferencing than after telephone contact only with a questionnaire score of 4 out of 5 versus 3.6 out of 5. Morgan et al. [15] also found that parents deemed video conferencing 26.9% more beneficial than telephone contact. Interestingly in 28.9% of the telephone contacts clinicians would have had a different treatment plan if video conferencing was used instead. Anxiety was significantly lower in the group using video conference.

3.3.4. Texting

Rempel et al. [19] used text messaging as intervention after nurse-led intervention for the transition from pediatric to adult care. Texting based interventions have been studied in multiple patient populations, for example in asthma and HIV and the intervention was received well but outcomes were not yet conclusive [24–26]. In patients with CHD, however, text messaging has never been studied. A lot of young adult patients with CHD are ill-informed about their heart defect and also have a low attendance rate during follow-up [27,28]. Text messaging was considered a possible solution. Patients included in the study were asked to send a text to the study nurse if they had any questions, as to increase patients' knowledge and to promote self-management skills. 67% of the participants chose text messaging as form of communication and contact was established between participant and nurse in 81%, yet this was mainly nurse-driven as only one participant asked a question without being prompted by a nurse. In 46% tailored information was provided to the participants. Text messaging was found an important additional method of communication as it resulted in full conversations which were in-depth and meaningful. Text messaging enabled the collection of data about the effectiveness of the clinic based intervention, also insight in the well-being and health of the teens was acquired [19].

3.4. eHealth encouragement for physical activity

Adults with CHD have a decreased VO_2 compared to healthy individuals. The congenital heart defects may explain these differences but low levels of physical activity among patients with CHD may attribute to this problem [29–32]. A previous study has shown improvement in exercise capacity in patients with a systemic right ventricle. A comparable study is still ongoing in adults with CHD [33,34]. Klausen et al. [20] performed a randomized controlled trial, in which 158 adolescents with complex congenital heart defects received exercise encouragement through internet, mobile applications, and text messages, as to improve exercise capacity and physical activity.

No beneficial effect was found by Klausen et al. with respect to physical fitness, physical activity, and HR-QOL after 52 weeks of eHealth encouragements through internet, mobile applications, or SMS.

4. Conclusion

A new era is coming in healthcare with the introduction of various eHealth and mHealth applications. These applications showed promising results in specific subgroups of patients with CHD. The current data, however, were insufficient to draw definite conclusions due to the low number of performed studies, and the large heterogeneity of selected patients and chosen interventions. Future research should define the place of eHealth and mHealth applications in the management of patients with CHD.

5. Expert commentary

This is the first review article to evaluate the current use, feasibility, and effect of eHealth interventions in patients with CHD. We found data to be scarce and heterogeneous, and predominantly performed in children and adolescents. This review article demonstrates the necessity of larger-scaled, high quality trials to assess the tremendous potential of eHealth in the field of CHD.

The lack of studies on mHealth in CHD patients is surprising, as mHealth is already implemented in patients with acquired heart disease to a much greater extent. A recent overview paper included 19 systematic review articles on mHealth in patients with acquired congestive heart failure. It described the effect of a broad range of mHealth interventions, such as telephone-based symptom monitoring, video consulting, and home-based measurements of vital parameters. This overview demonstrated that telemonitoring is effective in reducing hospitalization and mortality in patients with congestive heart failure, especially when physiological monitoring of blood pressure, heart rate, body weight, and ECG form part of the intervention. The authors suggested to add mHealth as an integral part of the care of heart failure patients [8,35]. Patients with atrial fibrillation seem to benefit from very different mHealth interventions. In these patients, remote monitoring of heart rate, using single lead ECG, was found to be more accurate in detecting recurrence of atrial fibrillation, compared to clinically performed ECGs or Holter-ECGs [36]. Moreover, mHealth provides the possibility to safely and quickly manage patients with a recurrence of atrial fibrillation [5], and to increase adherence to non-vitamin K antagonist oral anticoagulants [37]. In addition, eHealth is beneficial for patients with uncontrolled hypertension. Patients who received telephone support combined with remote telemonitoring showed better blood pressure compared to the control group [7].

The CHD population could benefit from the success of mHealth and eHealth interventions in patients with acquired heart disease in for instance the detection of atrial fibrillation [5]. Although the initial heart defect is corrected at a young age in the large majority of CHD patients, these patients require lifelong follow-up [38]. Although pathophysiology differs from patients with acquired heart disease, patients with CHD often suffer from similar symptoms, with cardiac arrhythmias being the most common reason for hospital admission, and heart failure the most frequent cause of premature death [39,40]. Therefore, lessons learned from mHealth interventions in patients with acquired heart disease should be used to setup studies on mHealth in CHD.

There is another reason to consider the CHD population preeminently likely to benefit from mHealth. A recent study by our group on the current use and future need of mHealth in CHD demonstrated this relatively young, and rapidly growing, patient population to be digitally well connected, with >90% of the patients being in possession of a smartphone. Although, a mere 14% of adult CHD patient already used some form of mHealth, the large majority (75%) expressed interest in the usage of mHealth [41]. For this patient population, mHealth has two important potential benefits. First, home-monitoring of vital parameters at a very young age was found to improve early recognition of clinical deterioration, and facilitate swift medical intervention, therewith decreasing cardiac morbidity and mortality [12,13,16]. The same is likely to hold true for patients at another stage in their lives. As CHD patients are often young of age, safety is a primary concern in de further development of mHealth interventions and further research is needed on this subject. Secondly, mHealth has the potential to put the patient into the lead, as it provides the possibility to monitor, diagnose, and treat patients at their request, and to facilitate patient–physician contact [17,18,20].

There are many drawbacks to perform mHealth studies in CHD patients, such as safety, privacy, and reimbursement issues. Moreover, the heterogeneity of mHealth interventions makes it difficult to define a shared focus. This review article demonstrated, as chosen interventions and included patient differed to such an extent, that it remains impossible to draw definite conclusions. Most studies evaluated the effect of perioperative home-monitoring in young patients undergoing corrective cardiothoracic surgery, mostly with success [12–16]. One study described the need for development of an online information portal, on which patient could find information on their condition and its implications [4]. A very different form of mHealth, in which contact between patients and their health care provider was used to facilitate communication through texting or video conferencing, was found to be satisfactory for both [17–19]. The lack of evidence, particularly in this highly attractive CHD population, is the reason for us to setup a trial that evaluates the effect of telemonitoring of vital signs in adult CHD patients who are symptomatic with heart failure and/or arrhythmias. This study is currently still ongoing.

5.1. Limitations

Our review was predominantly limited by the low number of performed studies, and the heterogeneity of the included patients and chosen interventions. Indeed, no adult CHD patients were included in any of the studies. This makes generalizability of these data difficult and drawing of any definite conclusions impossible. A large-scaled, randomized controlled trial, which includes a large variety of adult CHD patients, is much needed to evaluate the enormous potential of mHealth in these patients and to draw more definite conclusions.

6. Five-year view

In the following 5 years it is expected that progression of eHealth and mHealth will be immense and that successful implementation in daily healthcare is successful. Application development specifically for healthcare will be streamlined compared to the unrestrained application development in the current era. Also data security will be ensured as international regulations will have created an efficient way of personal data management. Direct access to monitored parameters by physician and patients will be available and direct feedback and subsequently adequate treatment will be implemented and ready. Also video conferencing via smartphones will have benefitted the patient–physician contact in for example immobile patients and will improve healthcare accessibility. Concluding, the management of patients with CHD, who will increase in number in the following years, will be strongly augmented by the use of mHealth. Additional research will provide information on which patients and which interventions are most (cost) effective. We anticipate insurance companies to collaborate with health care providers to incorporate beneficial and cost-effective eHealth and mHealth interventions in the standard care as we have seen in patients with acquired heart disease in the Netherlands.

Key issues

- Patients with CHD are expected to benefit from mHealth applications since they are relatively young, digitally skillful and in need for lifelong follow-up.
- eHealth showed promising results in the management of patients with CHD.
- Home-monitoring of weight and pulse-oximetry in infants with CHD predominantly showed a positive effect on interstage mortality.
- Videoconferencing was accepted positively and showed a reduction of anxiety and healthcare resource usage.
- Various forms of eHealth and mHealth showed potential in patients with CHD, but the number of data is scarce and definite conclusions cannot be drawn yet and more data is needed.

Funding

The work described in this study was carried out in the context of the e-Health Citrien program. The e-Health Citrien program is part of and funded by the Netherlands Federation of University Medical Centres (NFU). This work was also supported by Dutch Heart Foundation [grant number 2017 T 2].

Declaration of interest

The authors have no relevant affiliations or financial involvement with any organization or entity with a financial interest in or financial conflict with the subject matter or materials discussed in the manuscript. This includes employment, consultancies, honoraria, stock ownership or options, expert testimony, grants or patents received or pending, or royalties.

Reviewer disclosures

Peer reviewers on this manuscript have no relevant financial or other relationships to disclose.

References

Papers of special note have been highlighted as either of interest (•) or of considerable interest (••) to readers.

1. Van Der Bom T, Zomer AC, Zwinderman AH, et al. The changing epidemiology of congenital heart disease. Nat Rev Cardiol. 2011;8:50–60.
   •• This study shows the increasing population of adults with congenital heart disease, which emphasizes the need for research in this patient group
2. Van Der Bom T, Bouma BJ, Meijboom FJ, et al. The prevalence of adult congenital heart disease, results from a systematic review and evidence based calculation. Am Heart J. 2012;164:568–575.
3. Marelli AJ, Ionescu-Ittu R, Mackie AS, et al. Lifetime prevalence of congenital heart disease in the general population from 2000 to 2010. Circulation. 2014;130:749–756.
4. Etnel JRG, Van Dijk APJ, Kluin J, et al. Development of an online, evidence-based patient information portal for congenital heart disease: a pilot study. Front Cardiovasc Med. 2017;4:25.
5. Shacham J, Birati EY, Malov N, et al. Telemedicine for diagnosing and managing paroxysmal atrial fibrillation in outpatients. The phone in the pocket. Int J Cardiol. 2012;157:91–95.
   • Showing the benefits of mHealth in specific subgroups
6. Tison GH, Sanchez JM, Ballinger B, et al. Passive detection of atrial fibrillation using a commercially available smartwatch. JAMA Cardiol. 2018;3(5):409-416.
7. Bernocchi P, Scalvini S, Bertacchini F, et al. Home based telemedicine intervention for patients with uncontrolled hypertension–a real life non-randomized study. BMC Med Inform Decis Mak. 2014;14:52.
8. Carbo A, Gupta M, Tamariz L, et al. Mobile Technologies for managing heart failure: a systematic review and meta-analysis. Telemed J E Health. 2018.

9. Iribarren SJ, Cato K, Falzon L, et al. What is the economic evidence for mHealth? A systematic review of economic evaluations of mHealth solutions. PLoS One. 2017;12:e0170581.
10. Ponikowski P, Voors AA, Anker SD, et al. ESC Guidelines for the diagnosis and treatment of acute and chronic heart failure: the task force for the diagnosis and treatment of acute and chronic heart failure of the european society of cardiology (esc). Developed with the special contribution of the heart failure association (HFA) of the ESC. Eur J Heart Fail. 2016;18:891–975.
11. Turakhia MP, Kaiser DW. Transforming the care of atrial fibrillation with mobile health. J Interv Card Electrophysiol. 2016;47:45–50.
12. Castellanos DA, Herrington C, Adler S, et al. Home monitoring program reduces mortality in high-risk sociodemographic single-ventricle patients. Pediatr Cardiol. 2016;37:1575–1580.
13. Ghanayem NS, Cava JR, Jaquiss RDB, et al. Home monitoring of infants after stage one palliation for hypoplastic left heart syndrome. Semin Thorac Cardiovasc Surg Pediatr Card Surg Annu. 2004;7:32–38.
14. Harahsheh AS, Hom LA, Clauss SB, et al. The impact of a designated cardiology team involving telemedicine home monitoring on the care of children with single-ventricle physiology after norwood palliation. Pediatr Cardiol. 2016;37:899–912.
15. Petit CJ, Fraser CD, Mattamal R, et al. The impact of a dedicated single-ventricle home-monitoring program on interstage somatic growth, interstage attrition, and 1-year survival. J Thorac Cardiovasc Surg. 2011;142:1358–1366.
16. Siehr SL, Norris JK, Bushnell JA, et al. Home monitoring program reduces interstage mortality after the modified Norwood procedure. J Thorac Cardiovasc Surg. 2014;147: 718–723.e1.
17. McCrossan B, Morgan G, Grant B, et al. A randomised trial of a remote home support programme for infants with major congenital heart disease. Heart. 2012;98:1523–1528.
18. Morgan GJ, Craig B, Grant B, et al. Home videoconferencing for patients with severe congential heart disease following discharge. Congenit Heart Dis. 2008;3:317–324.
19. Rempel GR, Ballantyne RT, Magill-Evans J, et al. Texting teens in transition: the use of text messages in clinical intervention research. JMIR Mhealth Uhealth. 2014;2:e45.
20. Klausen SH, Andersen LL, Søndergaard L, et al. Effects of eHealth physical activity encouragement in adolescents with complex congenital heart disease: the PReVaiL randomized clinical trial. Int J Cardiol. 2016;221:1100–1106.
21. Paré G, Jaana M, Sicotte C. Systematic review of home telemonitoring for chronic diseases: the evidence base. J Am Med Inform Assoc. 2007;14:269–277.
22. Clark RA, Inglis SC, McAlister FA, et al. Telemonitoring or structured telephone support programmes for patients with chronic heart failure: systematic review and meta-analysis. BMJ. 2007;334:942.
23. Heidbuchel H. Telemonitoring of implantable cardiac devices: hurdles towards personalised medicine. Heart. 2011;97:931–939.
24. Prabhakaran L, Chee WY, Chua KC, et al. The use of text messaging to improve asthma control: a pilot study using the mobile phone short messaging service (SMS). J Telemed Telecare. 2010;16:286–290.
25. Juzang I, Fortune T, Black S, et al. A pilot programme using mobile phones for HIV prevention. J Telemed Telecare. 2011;17:150–153.
26. Cornelius JB, St Lawrence JS, Howard JC, et al. Adolescents' perceptions of a mobile cell phone text messaging-enhanced intervention and development of a mobile cell phone-based HIV prevention intervention. J Spec Pediatr Nurs. 2012;17:61–69.
27. Van Deyk K, Pelgrims E, Troost E, et al. Adolescents' understanding of their congenital heart disease on transfer to adult-focused care. Am J Cardiol. 2010;106:1803–1807.
28. Reid GJ, Irvine MJ, McCrindle BW, et al. Prevalence and correlates of successful transfer from pediatric to adult health care among a cohort of young adults with complex congenital heart defects. Pediatrics. 2004;113:e197–205.
29. Longmuir PE, Brothers JA, De Ferranti SD, et al. Promotion of physical activity for children and adults with congenital heart disease: a scientific statement from the American Heart Association. Circulation. 2013;127:2147–2159.
30. Diller G-P, Dimopoulos K, Okonko D, et al. Exercise intolerance in adult congenital heart disease: comparative severity, correlates, and prognostic implication. Circulation. 2005;112:828–835.
31. Fredriksen PM, Veldtman G, Hechter S, et al. Aerobic capacity in adults with various congenital heart diseases. Am J Cardiol. 2001;87:310–314.
32. Takken T, Giardini A, Reybrouck T, et al. Recommendations for physical activity, recreation sport, and exercise training in paediatric patients with congenital heart disease: a report from the exercise, basic & translational research section of the european association of cardiovascular prevention and rehabilitation, the european congenital heart and lung exercise group, and the association for european paediatric cardiology. Eur J Prev Cardiol. 2012;19:1034–1065.
33. Winter MM, Van Der Bom T, De Vries LCS, et al. Exercise training improves exercise capacity in adult patients with a systemic right ventricle: a randomized clinical trial. Eur Heart J. 2012;33:1378–1385.
34. Exercise training in grown-up congenital heart disease – Full text view – Clinicaltrials.gov [Internet]. [cited 2018 Apr 17]. Available from: https://clinicaltrials.gov/ct2/show/NCT02825472.
35. Bashi N, Karunanithi M, Fatehi F, et al. Remote monitoring of patients with heart failure: an overview of systematic reviews. J Med Internet Res. 2017;19:e18.
36. Kimura T, Aizawa Y, Kurata N, et al. Assessment of atrial fibrillation ablation outcomes with clinic ECG, monthly 24-h Holter ECG, and twice-daily telemonitoring ECG. Heart Vessels. 2017;32:317–325.
37. Desteghe L, Vijgen J, Koopman P, et al. Telemonitoring-based feedback improves adherence to non-vitamin K antagonist oral anticoagulants intake in patients with atrial fibrillation. Eur Heart J. 2018.
38. Baumgartner H, Bonhoeffer P, De Groot NMS, et al. ESC Guidelines for the management of grown-up congenital heart disease (new version 2010). Eur Heart J. 2010;31:2915–2957.
39. Zomer AC, Vaartjes I, Van Der Velde ET, et al. Heart failure admissions in adults with congenital heart disease; risk factors and prognosis. Int J Cardiol. 2013;168:2487–2493.
40. Koyak Z, Kroon B, De Groot JR, et al. Efficacy of antiarrhythmic drugs in adults with congenital heart disease and supraventricular tachycardias. Am J Cardiol. 2013;112:1461–1467.
41. Schuuring MJ, Backx AP, Zwart R, et al. Mobile health in adults with congenital heart disease: current use and future needs. Neth Heart J. 2016;24:647–652.
    - **Showing the willingness and need for mHealth in adults with congenital heart disease.**