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## **Creating a continuum of care : smart technology in patients with cardiovascular disease**

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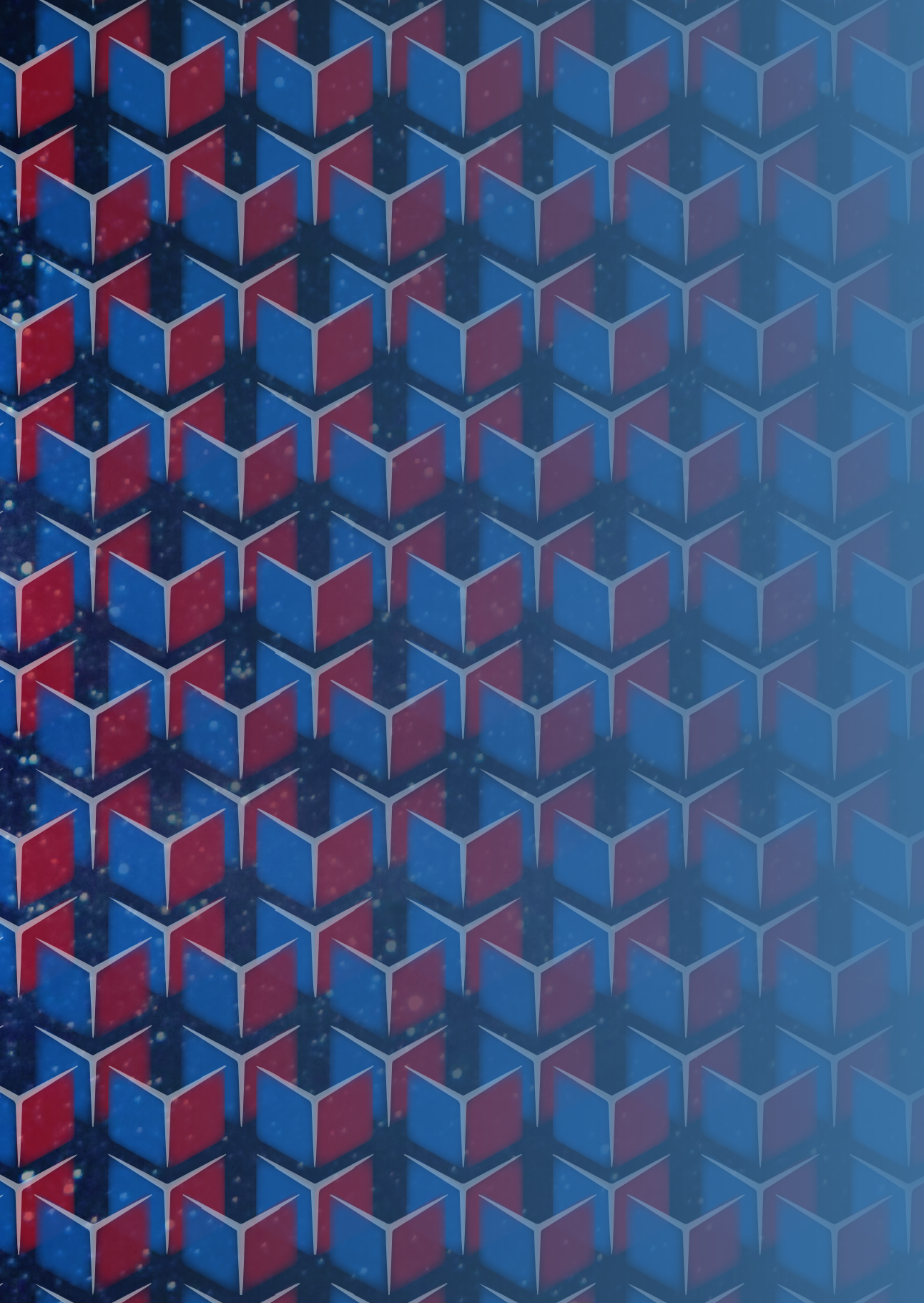


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## CHAPTER 9

# Adults with congenital heart disease: ready for mobile health?

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Submitted

## **Abstract**

### **Purpose**

Mobile health (mHealth) could improve outcome and reduce emergency care utilization of grown-up patients with congenital heart disease (GUCH). Inappropriate use of mHealth, however, can lead to data overload for professionals and unnecessary measurements for patients, increasing burden for both. We aimed to determine the clinical characteristics of patients with high emergency care utilization and to test whether these patients were willing to start using mHealth.

### **Methods**

Clinical characteristics and emergency care utilization of consecutive GUCH patients who visited one of the two participating cardiologists at the outpatient clinic of the Academic Medical Center in Amsterdam were studied retrospectively. All patients were approached to fill in an mHealth questionnaire. A frequency of three or more emergency visits in 5 years was defined as high emergency care utilization.

### **Results**

In total, 202 consecutive GUCH patients who visited one of the two participating cardiologists were studied. Median age was 41 years, 47% were male, and 51% were symptomatic. In the past five years, 134 emergency visits were identified. Of all patients, 8% had high emergency care utilization. High emergency care utilization was associated with patients being symptomatic, using anti-arrhythmic drug therapy or diuretics. In total, 75% of all patients with high emergency care utilization were willing to start using mHealth.

### **Conclusion**

GUCH patients who are symptomatic, those on anti-arrhythmic drug therapy and those on diuretics are suitable candidates to enroll in future mHealth initiatives because of both high care utilization and high motivation to start using mHealth.

## **Introduction**

Congenital heart disease (CHD) is one of the most common birth defects.(1-3) During the past decades, life expectancy of children born with a CHD has increased dramatically. At present, 95% of children with CHD reach adulthood.(1) However, many of the grown-ups with congenital heart disease (GUCH) are chronically affected by residual sequelae leading to unpredictable arrhythmias, heart failure and a reduced quality of life.(4-8) In general, GUCH patients have a high utilization of emergency resources, with emergency care utilization increasing as age progresses. (4) As the population of GUCH patients is increasing in number and age, total emergency care utilization of this population is expected to increase.(9)

Mobile health (mHealth) is the provision of medical care by mobile technologies capable of delivering health information, monitoring clinical signs and enabling direct care and patient education.(10) Using mobile technology, vital signs can be collected and sent immediately to a treating cardiologist. E-visits enable immediate and remote contact between doctor and patient.(11) Therefore, potential benefits of mHealth include rapid delivery of round-the-clock care, enhance daily monitoring and hence timely response and more convenience for patients and improve access for patients.(12) In order to improve outcome and reduce emergency care utilization careful selection of patients that are most likely to benefit from an mHealth intervention is warranted. If used in an inappropriate patient population, mHealth can lead to data overload for healthcare professionals and unnecessary measurements for patients, increasing burden for both.(13) Patients with a high emergency care utilization and high motivation to start using mHealth are suitable candidates to initiate new mHealth initiatives on. It is therefore the primary objective of this study to determine the clinical characteristics of GUCH patients with high emergency care utilization. It is the secondary objective to combine these findings with the results of an mHealth questionnaire, to test whether GUCH patients with high emergency care utilization are willing to start using mHealth.

## **Methods**

### **Population and data collection**

For this study, two cardiologists specialized in GUCH (BB & BM) approached consecutive patients who had an appointment at the outpatient clinic with them to fill in an mHealth questionnaire. These patients visited the outpatient clinic at the Academic Medical Center in Amsterdam between April 2016 and September 2016. Clinical characteristics and emergency care utilization of these GUCH patients were studied retrospectively. Clinical characteristics that were noted were: severity of the CHD (in accordance with the Bethesda conference) (14), history of cardiac surgery, history of pacemaker or implantable cardioverter defibrillator (ICD) implantation

and the use of diuretics or any antiarrhythmic drug therapy. In case of antiarrhythmic drug therapy, the indication was noted as well. Beta-blockers were considered an antiarrhythmic drug therapy if the drug was initiated or the dose was altered for symptoms of palpitations or treatment for arrhythmia control. Cardiac related symptoms were expressed by the New York Heart Association (NYHA) Functional Class. GUCH patients with a NYHA class II or higher were considered symptomatic. Emergency care utilization was defined as visits to the Emergency Room, Cardiac Care Unit or unplanned outpatient clinic visits. Outpatient clinic visits were counted if they included a visit to a cardiologist, cardiologist in training, heart failure nurse or dedicated CHD nurse at the department of Cardiology of the Academic Medical Center. An outpatient clinic visit was characterized as “unplanned”, if the electronic medical record (EMR) explicitly stated that the patient was seen in case of symptoms. Interventions that were noted following an emergency care visit were any type of open-heart surgery, aneurysm surgery, pacemaker or ICD implantation or replacement, diagnostic catheterizations, electrical cardioversions (ECV), catheter based interventions and bronchoscopy in case of hemoptysis. We defined high care utilization as a score of three or more emergency visits between June 1<sup>st</sup>, 2011 and December 31<sup>st</sup>, 2016.

All patients were approached to fill in an mHealth questionnaire on paper. Details of the questionnaire have been described previously.(15) Exclusion criteria for participating in this questionnaire were being mentally impaired (by physician’s discretion), illiterate in Dutch or being younger than 18 years of age.

### **Ethical Approval**

For the collecting of medical data of all the participating GUCH patients, permission was granted by the Ethics Committee (reference number W16\_057). For the questionnaire survey no approval from the Institutions’ Ethics Committee was required under Dutch law, since it was not burdensome for patients.

### **Data management and statistics**

SPSS 22 (IBM Corp. Released 2013. IBM SPSS Statistics for Windows, Version 22.0. Armonk, NY: IBM Corp.) was used for statistical analysis. To identify GUCH patients who would most likely benefit from mHealth, determinants were set off against an emergency care utilization of three or more emergency visits and/or interventions in the past five years. Variables were compared with a chi-squared test. A *P*-Value  $\leq$  0.05 was considered statistically significant.

## Results

### Population characteristics

In total 202 consecutive patients who visited the outpatient clinic and had an appointment with one of the two participating cardiologists (BB & BM) at the Academic Medical Center in Amsterdam between April 2016 and September 2016 were studied. Median age was 41 years (interquartile range 32 – 50, range 18 – 78 years), 47% was male and 51% was symptomatic. Of all patients, 19% had mild CHD, 61% moderate CHD and 20% severe CHD. A total of 83% had a history of cardiac surgery and 8% had a pacemaker or ICD implanted. A percentage of 31% used antiarrhythmic drug therapy and 9% used diuretics (Table 1). Only 5% were in NYHA class IV. All patients filled in the mHealth questionnaire.

**Table 1.** Comparison of high and low care utilization

	All patients N=202	Low care utilization N=186 (92%)	High care utilization N=16 (8%)	p
Median Age, years	41 (18-78)	40 (18-78)	42 (23-77)	
Male, %	47	46	43	.816
Congenital heart disease				
Mild, %	19	19	25	.548
Moderate, %	61	62	50	.352
Severe, %	20	19	25	.548
New York Heart Association Class				
Class I, %	49	51	13	<.001
Class ≥II, %	51	49	87	<.001
Event history				
Cardiac surgery, %	83	83	75	.363
PM/ICD implantation, %	8	8	19	.121
Medication				
Diuretics, %	9	7	44	<.001
Anti-arrhythmic, %	31	27	69	.001
mHealth				
Smartphone utilization (%)	93	94	87	.369
Ready to use mHealth (%)	71	70	75	.70

### Emergency visits

In the past five years, 202 patients accounted for 134 emergency visits. Of all 202 patients, 59 (29%) had one or more emergency visits. Of all 202 patients, 16 (8%)

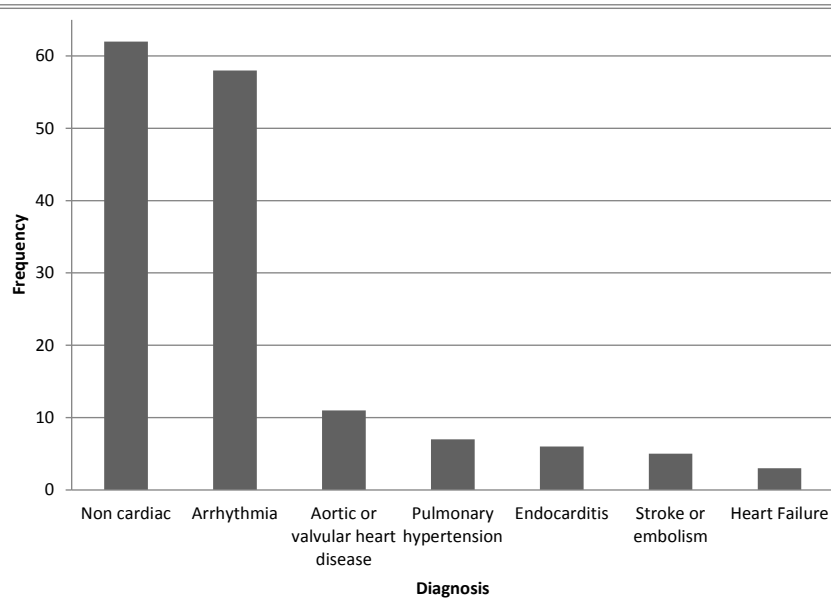
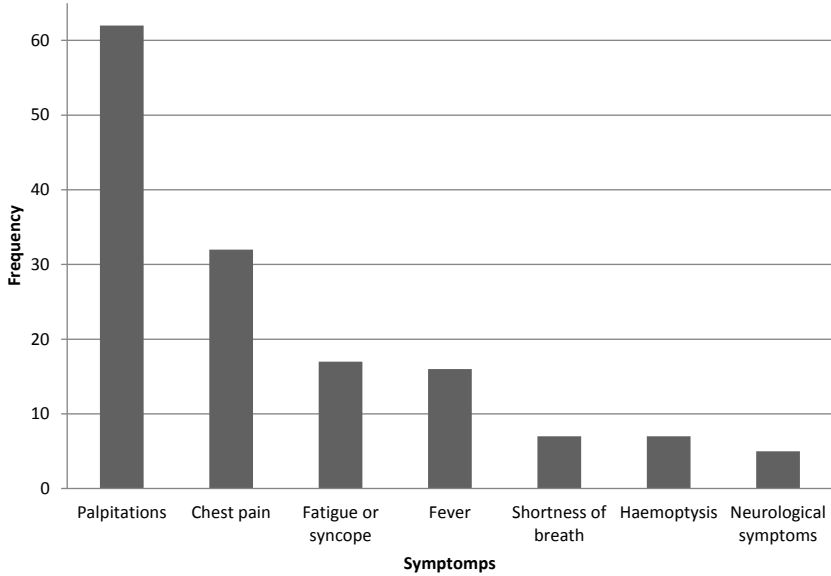
had high care utilization, compared to 186 (92%) with low care utilization. No significant differences in gender, history of cardiac surgery or severity of CHD were found between patients with high and low care utilization. Significant differences were found in NYHA class (87% vs 49%,  $P<.001$ ), use of diuretics (44% vs 7%,  $P<.001$ ) and use of antiarrhythmic drug therapy (69% vs 27%,  $P=.001$ ) (Table 1).

Table 2 and Figure 1 show all symptoms patients presented themselves with, consequent diagnoses made, and treatment administered. Most patients presented themselves with either palpitations (41%) or chest pain (24%). In 46% of all cases, no diagnosis of cardiac nature was found. In 37% of all cases, a patient was diagnosed with an arrhythmia (Figure 1).

**Table 2.** Information on emergency visits

<b>2A symptoms</b>	<b>N (%)</b>
Palpitations	55 (41%)
Chest pain	32 (24%)
Fever	16 (12%)
Fatigue	13 (10%)
Shortness of breath	7 (5%)
Hemoptysis	6 (4%)
Neurological symptoms	5 (4%)
<b>2B diagnoses</b>	<b>N (%)</b>
No diagnosis of cardiac nature	62 (46%)
Arrhythmia	50 (37%)
Endocarditis	6 (5%)
Pulmonary hypertension	6 (5%)
Stroke	5 (4%)
Valvular heart disease	3 (2%)
Heart Failure	2 (1%)
<b>2C therapeutic regimen consequences</b>	<b>N (%)</b>
No changes in therapeutic regimen	59 (44%)
Medication changes	52 (39%)
Electrocardioversion	29 (21%)
Interventions	4 (3%)
Planned interventions	3 (2%)

Emergency visits resulted in a variety of different actions. In 44% of all cases therapeutic regimen was not changed. Drug therapy was changed in 52 (39%) cases. In 8 (15%) out of 55 cases of palpitations, therapeutic regimen was not changed. Therapeutic regimen changes included 16 (29%) cases of ECV, 13 (24%)



**Figure 1.** Frequency emergency care visit reasons and subsequent diagnoses.

Legend: red: frequency of symptoms. Blue: frequency of diagnoses

cases of adjusting antiarrhythmic drug therapy after ECV, 7 (13%) cases of adjusting antiarrhythmic drug therapy only, 10 (18%) cases of initiating antiarrhythmic drug therapy and 1 (2%) case of radiofrequency ablation. The 32 cases of chest pain resulted in no action in 29 cases (91%). Therapeutic regimen changes included 3 (9%) cases of initiating antibiotic treatment for the suspicion of endocarditis.

### **Patient motivation to start using mHealth amongst patients with high emergency care utilization**

In total, 16 GUCH patients had high care utilization. Median age was 46 years, 56% was female and 87% was symptomatic. Of all 202 GUCH patients, 25% had a mild CHD, 50% a moderate and 25% a severe CHD. Antiarrhythmic drug therapy was used by 69% of patients and diuretics were used by 44% of patients.

Of all patients with high care utilization, 87% were in possession of a smartphone and 18% claimed to use mHealth already. Of all patients, 44% wanted information about their disease, while 44% wanted lifestyle advices via mobile technology. A total of 56% were willing to fill in vital signs on their smartphone, 56% were willing to fill in symptoms on their smartphone, 62% wanted advice in case of aberrant vitals, 62% wanted advice in case of symptoms of possible cardiac origin and 75% were willing to start using mHealth.

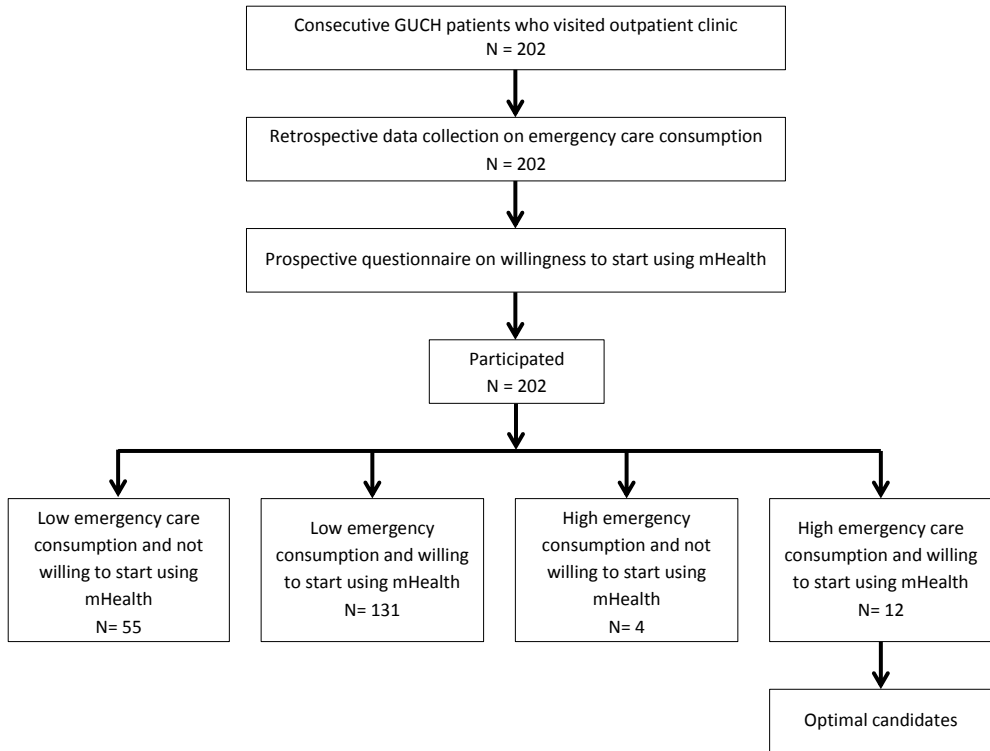
In contrast, in the low care utilization group, 131 (70%) patients were willing to start using mHealth (Figure 2).

### **Discussion**

To our knowledge this is the first study to determine suitability of candidates to enroll in new mHealth initiatives in GUCH patients. In our study, we identified symptomatic patients who are on diuretics or antiarrhythmic drug therapy to be more likely to visit the emergency room. These patients might benefit from mHealth, as emergency visits could be prevented via mHealth. In patients with few emergency visits, mHealth is less likely to be beneficial as it is a priori less likely to prevent an emergency visit. Therefore, our study could help to avoid initiation of mHealth with the goal to decrease emergency care utilization in an inappropriate patient population and could prevent unnecessary measurements for patients. Furthermore therapeutic regimen was not changed in 44% of all emergency visits. These visits might also be reducible via mHealth.

### **Emergency care utilization**

In this study, 29% of all participating GUCH patients had an emergency visit in the past five years. This was lower than the study of Mackie et al.(16) and Verheugt et al.(17), who reported that 68% and 50% of their study population had an emergency visit, respectively. Definitions of emergency care utilization between Mackie et



**Figure 2.** Flow-chart of patient selection.

al., Verheugt et al. and our study were comparable. It is therefore hypothesized that this difference is due to the fact that for this study, only emergency visits at the Academic Medical Center were analyzed. The Academic Medical Center is a tertiary hospital, treating patients from a large geographic region. In emergency cases, these patients are more likely to visit a local hospital close by their homes. These emergency visits are not counted in this study. Therefore, the frequency of emergency visits could be higher in our study population. In our study most patients presented with palpitations and chest pain. Arrhythmias were the most common final diagnosis. Only by one percent of patients heart failure was diagnosed, which was lower than in studies by Cedars et al (18) and Negishi et al.(19) There are several explanations: first, patients might have been admitted to other hospitals. Second, in this study, diagnoses were classified according to primary diagnosis. Some patients with arrhythmias visited with heart failure symptoms, but were diagnosed in the “arrhythmia category”. Third, two nurse practitioners specialized in heart failure had optimized treatment at the outpatient clinic, which could potentially have led to a reduction of deteriorations in heart function. Finally, in our study population,

31% had been hospitalized in the past five years. This was in line with the study of Mackie et al.(16) and Moons et al.(20)

### **Selecting GUCH patients for mobile health**

Our study showed that the majority of patients were willing to use mHealth applications. Several validated technologies that allow for remote ECG monitoring and automatic transmission are already available (21) and easy to use. For selecting the best candidate for possible future mHealth initiatives inclusion criteria should be: GUCH patients, experiencing frequent palpitations and/or chest pain, able to operate a smartphone and having high care utilization. Furthermore, having severe CHD, using diuretics and/or antiarrhythmic drug therapy, having an implant or experiencing symptoms can be taken into account in selecting the GUCH patients. Gender and age should not be a discrimination factor. Issues regarding privacy will need to be addressed, since this new technology will be sensitive for breach of privacy. Lastly, mHealth literacy is an important predictor of success of an mHealth intervention.(22) Therefore, acceptability should be taken into account when initiating mHealth initiatives in this group.

### **Limitations**

This study was limited by the fact that data collection was done in a single tertiary medical center, which could potentially affect generalizability. No data from other hospitals were incorporated in this study. Therefore, data on healthcare utilization presented in this study might be an underestimation, as GUCH patients that participated could have been admitted to other hospitals. Lastly, 16 patients in our study had a high emergency care utilization. This sample size is relatively small and the percentages derived from this sample size should therefore be cautiously interpreted.

### **Planned healthcare utilization**

This study was primarily concerned with the role of mHealth to decrease emergency care utilization. It might however be possible that frequent measurements of vital signs and remote doctor-patient contact will decrease the need for planned in-office visits as well. Moreover, mHealth could also contribute to the improvement of patient satisfaction and patient health engagement.(23) This should be measured in future mHealth initiatives as well.

### **Conclusion**

GUCH patients who are symptomatic, those on anti-arrhythmic drug therapy and those on diuretics are optimal candidates to enroll in new mHealth initiatives because of both a high care utilization and high motivation. Our study contributes to

appropriate patient selection for mHealth initiatives that aim to prevent emergency care utilization, thereby contributing to an efficient use of mHealth.

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