

Abstract

Building Mobile Technologies to Improve Transitions of Care in Adolescents with Congenital Heart Disease

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Abstract

Background: Congenital heart diseases (CHDs) are the most common type of birth defects. Improvements in CHD care have led to roughly 1.4 million survivors reaching adulthood. This emerging “survivor” population are often palliated but not cured. Thus successful transition from pediatric to adult care for CHD patients is crucial. Of adults with CHD, <30% are seen by adult CHD physicians. Transition and Transfer rates are even worse for minority and lower socioeconomic status (SES) populations. Few CHD transition programs exist, necessitating creation of a tool to assist in the transition to adult care for a diverse CHD population.

Objective: The objective of this project was to first complete a stakeholder needs assessment to inform the educational content and design of our mobile application; second, we aimed to develop the design, functional, and educational components for a mobile application guided by an adolescent CHD expert panel.

Methods: To inform our mobile application, we conducted a literature search regarding best practices in transition medicine, adolescent mobile applications, as well as expert CHD guidelines. We also conducted individual interviews in the cardiology clinic with CHD adolescents to understand possession of mobile phones, knowledge gaps, and missing transition readiness skills. We then partnered with 2 adolescent CHD expert panels, pediatric and adult cardiologists, and transition experts to further determine our educational content and mobile application design.

Results: We completed 327 individual interviews with CHD adolescents ages 15-22 years. Of these, 78.2% had moderate or severe CHD complexity; 41.6% of CHD adolescents were female; 12.7% were African American; and 35.8% were Latino. Of these patients, 36.5% had public insurance. Most patients had minimal understanding of their CHD, but expressed an interest in learning (42.2% of aged 15-17 years and 47.9% aged 18-22 years). Average transition readiness scores reflected an average of 49.4% readiness for those aged 15-17 and 58.6% for those aged 18-22. Of the adolescents, 95.8% had access to a smartphone. The adolescent expert panel expressed the need for an application tailored to their specific CHD, for quick access to specific educational questions (eg, “can I exercise”), for a forum to tell their stories or hear from others with CHD, to have mentorship, and to have a checklist so they could know what needed to be done during their transition. They also desired to make CHD clinic appointments and have a way to ask questions on the application. We subsequently built a mobile application incorporating assessments of transition readiness and knowledge, a CHD diagram, a medical summary, as well as the recommended blog, checklist, and question/answer space.

Conclusions: Based on our data of average CHD knowledge and transition readiness scores, CHD adolescents are largely not prepared for the transition and transfer to adult care. The vast majority of adolescents possess a smartphone, regardless of SES or race/ethnicity. Adolescents with CHD informed areas of focus for a mobile application to aid in the transition process that

drove the creation of our mobile application. Next steps are to conduct usability testing, to further build CHD educational content, to perform alpha and beta testing, and use focus groups to refine our current mobile application.

(*iproc* 2017;3(1):e36) doi:[10.2196/iproc.8583](https://doi.org/10.2196/iproc.8583)

KEYWORDS

adolescent health; chronic disease; health disparities; mobile health (mHealth); patient empowerment; patient involvement; self-efficacy; smartphone; user centered design

Multimedia Appendix 1

Full paper.

[[PDF File \(Adobe PDF File\), 5MB - iproc_v3i1e36_app1.pdf](#)]

Edited by T Hale; This is a non-peer-reviewed article.submitted 27.07.17; accepted 25.08.17; published 22. 09.17

Please cite as:

Lopez K, O'Connor M, King J, Alexander D, Challman M, Lovick D, Goodly N, Bonaduce De Nigris F, Smith A, Fawcett E, Mulligan C, Thompson D, Fordis M

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iproc 2017;3(1):e36

URL: <http://www.iproc.org/2017/1/e36/>

doi: [10.2196/iproc.8583](https://doi.org/10.2196/iproc.8583)

PMID:

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