Clinical Adoption of Mobile Technology to Support Self-Management of Pediatric Cystic Fibrosis in Sweden: A Qualitative Case Study

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Abstract

**Background:** Mobile health technologies have potential to improve self-management and care coordination of pediatric chronic diseases requiring complex care, such as cystic fibrosis. Barriers to implementation have included a lack of support and infrastructure to use mHealth in the clinical microsystem. Coproducing mHealth technology with patients, clinicians, and designers may increase the likelihood of successful integration in the clinical setting.

**Objective:** This study explored the development, adoption and integration of a new, coproduced mHealth platform (Genia) for the management of pediatric cystic fibrosis in Sweden.

**Methods:** A retrospective, qualitative case study approach was used. The case was defined as the process of introducing and using Genia at the Pediatric Cystic Fibrosis Center at Skåne University Hospital in Lund, Sweden. Data sources included interviews, presentations, meeting notes, and other archival documents created between 2014-2017. To be included, data sources must have described or reflected upon the Genia adoption process. Iterative content analysis of data source materials was conducted by two qualitatively trained researchers to derive themes characterizing the mHealth clinical adoption process.

**Results:** Four core themes characterized successful clinical integration of Genia at Lund: a cultural readiness to use mHealth; the use of weekly huddles to foster momentum and rapid iteration; engagement in incremental “Genia Talk” to motivate patient adoption; and a co-design approach toward pediatric chronic care.

**Conclusions:** Principles of quality improvement, relational coordination, user-centered design, and coproduction facilitate the integration of mHealth technology into clinical care systems for pediatric CF care.

**Keywords:** Cystic fibrosis; pediatrics; qualitative methods; technology diffusion; users’ views
Introduction

The longitudinal care of children diagnosed with Cystic Fibrosis (CF) – an autosomal recessive genetic disorder affecting lung capacity - is characterized by substantial personal, familial, and medical burden [1,2]. To decelerate the decline in lung functioning, children must engage in respiratory and physical therapies up to 2 hours per day, adherence to which often decreases as children age through adolescence [3]. Guidance from healthcare providers is frequently disconnected from this daily routine and the personal goals of pediatric CF patients [4]. For pediatric CF, this disconnectedness derives in part from the traditional model of episodic care delivery, which hinders an uninterrupted approach and may result in fragmented clinical care [5]. The challenge to coordinated care particularly impacts young people during a developmentally vulnerable time, when they move from clinician-regulated pediatric care to increasingly autonomous self-management of their illness [6]. Successful transition to adult CF care is dependent on consistent, appropriate, and increasingly independent maintenance of a care regimen [7]. Encouraging these patterns of behavior in late childhood and early adolescence fosters stability and reliability of personal management of chronic illness into adulthood [8].

Technology-based “mHealth” (i.e., mobile health) platforms offer a transformational mechanism for improving clinical care in both preventive medicine and chronic disease management [9,10]. One strength of mHealth as a disease management tool is its ability to leverage existing mobile technology infrastructure and the ubiquity of smartphones across populations [11]. For adolescents, frequent users of mobile technology, mHealth applications show potential as a strategy for improving self-management and adherence to treatment regimens for numerous chronic conditions [12]. Successful use of technology-based support systems to foster self-management, however, is not without challenges. Usability studies identify barriers to the uptake and adherence of various mobile and electronic health systems used by clinicians and patients [13,14]. These barriers include low self-efficacy with mHealth.
platforms; perceptions that the technology will not enhance clinical outcomes; privacy and security concerns; and a lack of infrastructure to support the use of mHealth applications [15,16].

Integral involvement of end users in the development of mHealth apps - such that the technology is “coproduced” by designers, clinicians, and patients - may be one strategy to overcome implementation challenges. Co-production refers to the joint creation of healthcare services for managing the treatment of a health condition [17]. By engaging end users in mHealth development, this joint design approach may avoid common implementation barriers and enhance the likelihood that these new technologies will be adopted in clinical settings and used by target audiences [18,19].

The purpose of this study was to provide a retrospective, case analysis of the development, adoption and integration of a new, coproduced mHealth platform for the management of pediatric CF in Sweden. Genia is an app-based Patient Support System (PSS) designed to foster collaborative care and enhance self-management for pediatric patients living with chronic conditions. In 2014, Genia was introduced to the Lund Pediatric CF Center at Skåne University Hospital (“Lund”) in its design phase, and co-developed with adolescent patients and CF providers at the center. Since then, Genia has been adopted by all four pediatric CF Centers in Sweden, and is used by approximately 30% of the total CF pediatric patients in the country. The adoption of Genia at Lund remains particularly successful, with a majority of pediatric CF patients using the app. The present case study examined the introduction of Genia at Lund, so that successful contributors to clinical integration of a technology-based PSS may be disseminated to other pediatric CF centers in Sweden and abroad, and potentially to other pediatric chronic conditions.

Methods

The mHealth Patient Support System: Genia
Genia is a mobile iOS PSS created by Swedish-based company Upstream Dream to optimize consensus-building in pediatric care by improving communication between patients and clinical teams, fostering disease self-management, and aligning patients’ goals with clinical treatment plans (see Figure 1).

**Figure 1. Genia Flow**

By doing so, Genia aims to facilitate timely, meaningful, and appropriate clinical care and ultimately to improve patients' quality of life. Through Genia, patients (or parents, depending on the patient’s age) can record daily health observations and symptoms between visits (e.g., physical activity; gastrointestinal problems), track medications, and complete pre-visit reports including treatment preferences and goals prior to a clinical appointment. This patient-reported information allows patients to document their disease activity and preferences in real-time in-between clinical visits (see Figure 2).
Patient data is then integrated in the national CF quality registry and in the care flow within the clinical setting. Clinical providers - including physicians, physiotherapists, and others - are able to review the patient pre-visit reports as an Adobe PDF file in the national CF quality registry prior to the clinical visit to better inform the visit and foster opportunities for shared decision making and goal-setting. Patients and providers also use Genia to collaboratively document agreed upon therapeutic decisions, actionable steps, and other information derived during the clinical visit. This presents a mechanism to foster patient self-management, build trusted patient-provider relationships, and increase compliance with mutually agreed upon care plans.

Grounded within principles of user-based design [20], feed-forward systems [21], and co-production [17], functional features of Genia were created and tested through small-scale, iterative design cycles with patient and family representatives and clinical CF providers within the Lund Pediatric CF clinical microsystem. These learning collaboratives formed the backbone of Genia development by ensuring that
technological modifications of the app were grounded in end user’s lived experiences. This user-centered perspective is also illustrated in the key features of the app, which identify patients as the experts in their disease state and better enable them to provide their voice to the care they receive. Genia is currently available for download from the iTunes App Store in an iOS platform in Swedish and English.

**Study Design**

We conducted a retrospective, descriptive, qualitative case study [22] of Genia adoption at Lund as part of a larger formative evaluation of Genia within the clinical, pediatric CF setting in Sweden. The case study method was considered most appropriate for several reasons, including: its holistic approach to describing how and why Lund was successful; the emphasis on exploration of a phenomenon in “real-life” clinical settings where the researchers observe but do not manipulate behaviors or processes under examination; and the ability to conduct a retrospective analysis by examining historical artifacts documenting the Genia development and adoption process [22]. This study was reviewed and determined to be exempt by the Committee for the Protection of Human Subjects at Dartmouth.

**Setting**

The “case” was defined as the process of introducing and using Genia at the pediatric CF department at Skåne University Hospital. Located in Lund, Sweden, Skåne University Hospital represents one of only four pediatric hospitals in Sweden. The Lund CF Center is a regional center for specialized CF care in accordance with the European Cystic Fibrosis Society Standards of Care, and serves approximately 60 pediatric patients annually. The pediatric clinical team at Lund consists of four physicians, two nurses, two physiotherapists (i.e., physical therapists), one dietician, one social worker, and one psychologist. This team meets weekly to discuss care plans and clinical issues with incoming patients. Pediatric CF patients located geographically close to the center typically visit the clinic every two months. Those living outside the region visit with the Lund clinical staff 2-4 times per year. Lund has a long tradition of
emphasizing the role of physiotherapy for the care of pediatric CF patients. Reflecting this tradition, at each clinical appointment, physiotherapists have an hour-long appointment with the patient prior to the physician’s visit with the patient.

Genia was initially introduced to the Lund CF Center in late 2014. Currently, 87% of Lund CF pediatric patients are members of the Genia PSS. Additionally, the pediatric Lund CF clinical staff indicate that 85% of all care team meetings (i.e., clinical visits between pediatric CF patients and a provider) are supported by Genia through the use of a pre-visit report.

**Data Sources**

Consistent with the case study methodological approach, we employed a data triangulation strategy in which data were extracted from multiple sources that were created between late 2014 and July 2017. Data sources included interviews with Lund providers and the Genia design team, design and implementation meeting notes, design team and clinical team emails, archived presentations, Genia progress reports, and other documents. To be included in the analysis, data sources must have described or reflected upon the early adoption and integration process of Genia at Lund. Some archival data sources were translated from Swedish to English using Google translate or by a bilingual member of the Genia design team. All data sources were organized and condensed into a tabular case record in Excel in preparation for analysis [22].

**Data Analysis**

Data analysis was conducted by two qualitatively-trained researchers, unaffiliated with either the Genia design team or the pediatric Lund CF team. We applied iterative, conventional content analysis [23] in the coding process. Conventional content analysis is an appropriate approach when there is not a strong theoretical framework directing the analysis, the aim of the investigation is descriptive, and study design is primarily observational [23]. Because of this, our analytic approach was primarily inductive, in which
we allowed themes to emerge from the raw data. We identified themes within three temporal stages of Genia adoption: 1) PSS introduction to the CF team, 2) facilitators to widespread adoption, and 3) integration into clinical flow.

The first researcher conducted the initial data analysis, using the aggregate case record as the full data source. Following immersive review of the data, an initial round of preliminary coding was performed for the entire case record [24]. Due to the varied types of data sources, we employed multiple coding techniques, including descriptive coding to document the data source and timeline, and process coding to identify the strategic actions during Genia adoption and implementation [24]. When possible, we also used direct words or phrases from the data source as emergent, in-vivo codes. During the second round of coding, we looked for patterns of codes within and across the temporal stages of Genia adoption, expanding, synthesizing, reframing, or rephrasing codes as necessary. Larger themes were described and illustrated with exemplars. The second researcher reviewed the case record and the thematic and illustrative evidence. Clarifications and discrepancies were resolved through consensus discussion. To enhance the credibility of the findings, the final set of themes were provided for review to one member of the pediatric Lund CF team and two members of the Genia design team.

Results

Four core themes characterized the successful adoption and integration of Genia at Lund. Illustrative quotes are excerpted from interviews with pediatric Lund CF providers.

Cultural Readiness to Use mHealth

Attitudinal and structural characteristics of Lund contributed to a pre-existing culture which was receptive to the introduction of a new mHealth technology. The Lund provider team had undertaken informal quality improvement (QI) projects prior to Genia, and were engaged and motivated to continue a QI-type approach to their clinical work.
“I think we always have that in mind to work ‘Lean’ [Lean Six Sigma] and to make quality improvement better at the clinic.”

Additionally, Lund providers indicated that Genia represented a more “modern” way of engaging in their clinical work with pediatric CF patients, particularly due to its technology-based platform, and thus it was consistent with their attitudinal ethos of continual improvement.

Several structural characteristics at Lund also contributed to the success with which the clinic adopted Genia. The historical prominence of the physiotherapist in pediatric CF care management yielded a trusted, internal point person to manage the effort of introducing Genia. The lead physiotherapist at Lund served as the primary "champion" of Genia and was the person who initially familiarized the wider clinical team to the app. Because of her role, she was influential in the decision by other members of the clinical team to try Genia.

“It's a tradition in Sweden and especially in Lund that the physio[therapist] is very important and mostly everyone listens to the physio. So if the physio says something, I really believe that everyone is listening.”

The second physiotherapist at Lund supported the lead physiotherapist’s efforts and likewise served as a Genia champion. The presence of two clinical champions at the site allowed for a collaborative approach and shared responsibility for the workload associated with Genia onboarding.

“You have to be at least two to get this project working because it’s hard to do everything by yourself. You need two fighting spirits.”

The physiotherapists’ historical leadership role in pediatric CF care not only helped with onboarding other clinical providers to Genia, but also helped with onboarding patients. The physiotherapists represent the most familiar clinic-based providers to the patients due to the extended time they spend with patients (i.e., one hour) prior to each appointment. The close, trusted nature of the physiotherapist-
patient relationship supported the physiotherapists’ ability to introduce Genia to the Lund pediatric patients.

Finally, because the Lund CF clinic is relatively small (~60 patients), and the pediatric CF provider team is also small (i.e., 11 members), logistical coordination and communication regarding Genia was easier. The team already met weekly to discuss patient issues, and thus integrating Genia into these team meetings was a “natural” way to incorporate Genia into a regular clinical discussion.

**Weekly Huddles Fostered Forward Momentum and Rapid Iteration**

Short (i.e., 15-minute) weekly clinic “huddles” served as the critical process mechanism for fostering continued, forward momentum in adopting Genia within Lund. Huddles were facilitated by a Genia design-team member, and attended by the physiotherapist champions, other clinical team members, and adolescent CF patient “lead users.” Huddles offered opportunities to provide support for using Genia, understand barriers to use, and document good practices. Huddles were characterized by a user-centered design approach, in which clinical and patient users would test features of the app during the prototype development phase and provide weekly feedback to the Genia design team, who would modify the app based on this feedback. The huddles thus facilitated iterative feed-forward / feedback problem-solving cycles that allowed for rapid identification of challenges to effective Genia use, and rapid implementation of responsive action plans. For example, during one huddle discomfort with using the technology was revealed as a potential barrier to use. The design team was able to quickly develop an instructional video which clinical team members could view repeatedly, to increase their proficiency with the app. The team’s commitment to weekly meetings ensured that progress continually moved forward.

“It’s been very important to have weekly contact with Genia. To remind you to ‘Think Genia!’”
Co-decision making during the huddles about Genia development, and a patient-centered approach in which the pediatric CF patients and the clinical providers were considered the "experts," both fostered engagement by the primary end users and enhanced motivation for continued Genia use. Patient and family lead users offered new ideas for upcoming iterations, provided a platform for peer support, and operated as ambassadors for spread. Huddles also fostered motivation through sharing of successful patient or provider stories of Genia use and lessons learned. Thus, the huddles represented the primary mechanism by which Genia progressed from initial design and limited use to wider scale adoption.

**Engagement in Incremental “Genia Talk” Motivated Patient Adoption**

The physiotherapists at Lund were primarily responsible for introducing Genia to patients. Several strategies for doing so were collectively referred to as “Genia Talk” by the physiotherapists. When possible, the physiotherapists introduced Genia to patients as early as possible in their care management. This communicated to the patient the integration of Genia with the usual care offered by the clinic.

*"The physiotherapists made Genia their tool. They signal very clearly to all patients that Genia is a way of working for them. 'This is how we do it in Lund.'"

Physiotherapists utilized a tailored, stepwise approach to the introduction of the app. Rather than showing patients (and their families) the entire app all at once, the physiotherapists selected one feature of the app to focus on with the patient at a particular visit (e.g., how to record a daily observation), tailored to a current clinical need. At the next clinical visit, the physiotherapists would check on progress with that feature of the app, and introduce another new feature (e.g., how to track medications).

*"We present Genia and what we can, together, benefit from in the app. We don’t try to present everything at once, but take small steps forward."
Additionally, at every visit, the physiotherapist would ask to collaboratively complete the pre-visit report in Genia with the patient, if the patient had not completed the pre-visit report on her own. This supported and gradual approach to onboarding patients was a central feature to the successful adoption of Genia by patients. By allowing patients to learn the app in a way that was responsive to their current needs, patients incrementally experienced the heightened value of Genia over time, without increased burden. As more and more patients began using the app in a successful way, word-of-mouth spread patient interest in using Genia, which also contributed to a transition to wider usage.

Co-Design Approach toward Pediatric CF Care

Emerging from the weekly huddles and improved engagement with patients was a process characterized by co-design strategies, where conversations and interactions were iterative and collaborative. These co-design strategies were profiled by the Lund providers in contrast to previous practice strategies marked by one-sided conversations and asymmetric information sharing. The co-design strategy ensured that the app was viewed as relevant, usable, and valuable to both patients and clinicians, thus overcoming potential barriers to implementation during the design phase, rather than waiting until after the app was completed. Thus, coproduction of the app itself was inherent to the success of the integration process.

In Genia-supported CF care, patients were able to share challenges and insights prior to meeting with their care team, which permitted care team members to prepare and more efficiently and effectively interact with them. One clinician said, “Being prepared for the visit, both family and patient” was made possible by the pre-visit report function through Genia. The functionality of Genia also permitted the co-creation of care notes, which was an outcome driven by the pre-visit report function. The efficiency of the structured visit, and “knowing what to ask,” helped the clinicians focus on the treatment plans for their patients rather than on managing the visit itself.
Discussion

Principal Findings

This descriptive case study contributes to a small body of literature on technology-based interventions to improve CF self-management [25,26] and is one of the first to document the development and adoption process of a mHealth app for pediatric CF patients in a clinical setting. By illustrating successful features of integration, our findings highlight cultural characteristics of the clinical setting which may be more likely to support the feasible integration of new technologies, as well as mHealth design components that contribute to success.

The current case reveals how the team-based institutional culture of a CF practice in Sweden complemented readiness for adoption of a novel mHealth patient engagement tool. Multiple characteristics of the clinic itself set the stage for successful integration, including a cultural ethos of QI, desire for more modern ways of providing care, relational coordination within a small care team [27], and mHealth champions who represented the most influential clinical team members both within the team and with patients, and thus could foster shared aims. These characteristics, what some have referred to as an "implementation climate," [28] essentially primed Lund for successful adoption of Genia. Organizational readiness of the clinical setting thus plays a gate-keeping role in mHealth integration [29]. As such, it offers important insights into the selection of settings which are likely to successfully adopt mHealth technologies for pediatric chronic illness management. This approach, however, is a resource-intensive process. The cultural and contextual characteristics of many pediatric clinical settings may reduce their ability to meet weekly for QI huddles, or to engage patients in the intensive mHealth design process.

Triangulation and qualitative analysis of multiple data sources supported findings that weekly team huddles during the adoption phase of Genia enhanced routinization communication practices and the
collective belief in the value of a technology-based application to engage CF patients. In essence, these weekly huddles served as the primary mechanism which operationalized the iterative, user-focused design process. Ample research on the development of mHealth technology promotes the incorporation of the end-user in the design process [30]. However, often this user input is incorporated late in the design phase, or episodically. Our case demonstrates that weekly meetings between key stakeholders (i.e., patients and clinicians) and the technology design team beginning early in the app development process was critical to integration. Not only did this human-centered design approach [30] allow for frequent, iterative design cycles based on user feedback (i.e., feed-forward / feedback information cycles), but it enhanced the commitment to use Genia due to a collective feeling that Genia is “for us, by us.”

The gradual, patient-specific onboarding process used by the physiotherapists enabled patients to learn to use Genia in an incremental manner. By highlighting features of the app that were useful to patients as needed, patients saw the increasing value of Genia without being overwhelmed by the capabilities of the technology. Since ease of use is one of the most frequently cited barriers to mHealth adoption [13,15], this slow and steady process of exposure, always with the direct help of the physiotherapist, was central to patients’ positive experiences with the app.

Limitations

There are several limitations to the current case study report. The sample of qualitative data was relatively small and examined retrospectively, which limited our ability to pursue clarification of historical artifacts. Further, our case study examined only one clinical setting in Sweden, limiting the generalizability of the findings. Thus, results presented here should be regarded as preliminary. We recognize that direct patient’s perspectives (e.g., patient interviews) were not included in the data sources, as this case was focused more on the implementation and dissemination of the technology
within the Lund clinical setting and among its clinicians. Patient perspectives are necessary to directly examine how patients perceived the clinical integration of Genia at Lund. Our report may have been limited by the Swedish and English language challenges of communicating across cultures. Although the case report was developed in partnership with bilingual partners and many clinicians spoke both English and Swedish, the nuance of the details must be read with caution as translations and interpretations may vary. Finally, this study only examined the process of adoption and implementation of Genia, and did not examine the impact of Genia on patient outcomes, such as improved self-management, treatment adherence, or quality of life. These offer important research directions for the use of Genia with pediatric CF patients.

Conclusions

This qualitative case study offers preliminary evidence for strategies necessary for successful adoption of a mHealth app within a pediatric chronic illness clinical setting. Although originally designed for pediatric patients with CF, the process described here could be applied to any pediatric chronic illness requiring extended self-management.

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**Conflicts of Interest**

A Hager, M Montan, and R Bergquist are employees of Upstream Dream, a private company that developed the Genia app. Authors affiliated with The Geisel School of Medicine at Dartmouth (M Longacre, S Grande, and G Kotzbauer) have no financial conflicts of interest to report.

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