

Designing Health Information Technologies to Support Integrated Care

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Abstract

Providing care for chronic conditions involves complex coordination. Integrated care is required, involving collaboration and synchronization among different kinds of care providers such as physicians, psychologists, and paraprofessionals. Integrated care also involves long-term treatment over months or years, resulting in communication challenges that can diminish the quality of provided care. The challenges of integrated care, therefore require innovation in health information technologies (HIT). In this paper, we provide empirical evidence from fieldwork we performed in an organization providing intensive behavioral and mental health services for children. Our fieldwork in this context provides an understanding of unique information needs for integrated care. We present design principles for HIT, which we have applied in designing a novel HIT aimed at behavioral data management, and validated through a long-term deployment study. We discuss the potential of these design principles for developing HIT to support the unique information needs of integrated care.

Introduction

Chronic conditions such as diabetes, asthma, and autism spectrum disorders affect individuals for months, years, or for life. Chronic conditions involve long-term care that requires coordination which has differing complexities from the care required for acute illness or injury. The delivery of healthcare services is changing in response to an increase in chronic conditions. Care is provided by teams often distributed across agencies, rather than by a single physician. Thus, integrating care that spans time, providers, and agencies is a new challenge in supporting healthcare services. The design of health information technologies (HIT) must meet this challenge by addressing the needs of care teams within an integrated model of care. Integrated care is emerging as the dominant healthcare model, but HIT has not adapted to the needs of this model. For example, team-based care is the new approach used by Kaiser Permanente, the largest non-profit healthcare system in the world, to address the need for a variety of specialists and the challenges of long-term care, but its leadership acknowledges that HIT is not supporting their team-based model¹. The collaboration of a care team has also been extended to include engagement of patients, caregivers, and community organizations². However, HIT often fails to enhance collaboration and communication³, a problem that reveals adherence to an older model of autonomous and paternalistic practice¹ with a focus on episodic encounters with the healthcare system². Design principles are needed to drive the development of novel HIT that meets the needs of integrated care. The role of HIT in integrated care has been defined to some extent^{1,4}, but further research is needed to determine how HIT should be designed to fill this desired role. For example, care teams should share data for monitoring progress and continuously improving care based on systematic assessment of what is and is not working¹. Progress monitoring requires information exchange that gives team members appropriate access to the historical record at the right time and place to meet their individual needs, so they can assess what is working and can contribute to team-based decisions about care moving forward.

Behavioral health is a context where research on HIT has demonstrated relevant links to design issues in other healthcare contexts⁵⁻⁷. Care teams in behavioral health for children monitor and address inappropriate and undesired behaviors that affect a child's ability to learn and develop interpersonal relationships. Care teams focused on children are distributed across home, school, and clinic. To understand the needs of integrated care, we have investigated and designed for school-based teams because they are the primary record keepers and are required by law to document services provided to children with special needs⁸. In this paper, we present empirical evidence of challenges for supporting integrated care in behavioral health. We developed a set of design principles, and used them to design a novel HIT aimed at supporting data management and decision-making of behavioral care teams. Finally, we conducted a long-term deployment study to validate our design principles, and assess the role of our HIT within integrated care.

Methods

Our research process consisted of four phases, illustrated in Figure 1. During phase 1, we conducted a contextual study to observe the challenges that care providers face in providing integrated care and understand their

information needs. During phase 2, we analyzed our findings to develop a set of design principles for HIT aimed at supporting integrated care. In phase 3, we used these design principles to develop a novel HIT system for management of behavioral health records. During phase 4, we validated and assessed our design principles through a deployment study of our HIT system.

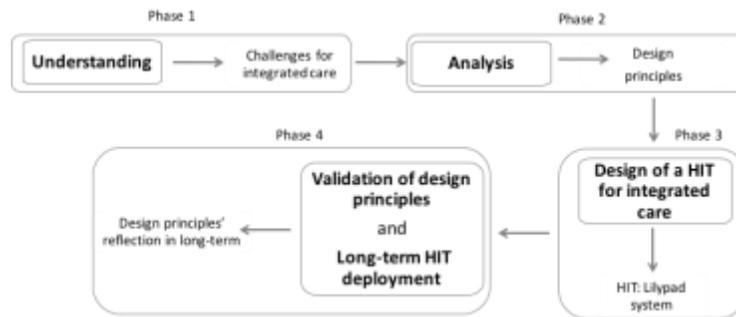


Figure 1. Research process

Phase 1. We conducted fieldwork to understand the practices of collocated care teams in one organization. We documented collaborations in care teams that provide behavioral and mental health services within a school setting. Two members of our research team conducted a total of 61 hours of non-participatory observation in two behavior disorder classrooms in the school. Twice a week, researchers observed the classroom activities using the basic framework for analyzing observational data to document activities, materials, places and stakeholders⁹. The observation notes were analyzed using inductive thematic analysis¹⁰. We used affinity diagramming¹¹ to synthesize the findings of the contextual study.

Phase 2. Based on the challenges found in the previous phase, the research team performed inductive analysis, ideation, and iterative prototyping to develop design principles for designing HIT aimed at supporting integrated care.

Phase 3. Once we developed the design principles to design HIT for supporting integrated care, we applied them during an iterative design process to create the Lilypad system. We used interaction design techniques such as sketching¹² to create low-fidelity prototypes of a HIT to support integrated care. We refined our low-fidelity prototypes creating mockups with input from the care teams, and continued with rapid prototyping until the Lilypad system met their needs.

Phase 4. We conducted a long-term deployment study of Lilypad system in two behavior disorder classrooms and one regular classroom that focuses on behavioral intervention. Two members of our research team conducted a total of 554 hours of non-participatory observation over the course of 11 months across two school years. Researchers took observation notes using the basic framework for analyzing observational data⁹. The observation notes were analyzed using thematic analysis¹⁰ and the constant comparative method.

Challenges of integrated care in behavioral health

The care teams we observed consisted of four care providers: one teacher, two aides, and a social worker. In each classroom, care receivers (*i.e.*, children) have individual desks as well as small tables in the back of the room for small group work led by a provider. Providers work closely with each other in the classroom, including while instructing the children in small groups. Providers often work together collecting behavioral data. Paper-based data sheets are used to collect care receivers' behavior information. Each care receiver has a daily data sheet. Providers share the data sheets and collectively write comments about care receivers' behavior. Other providers such as social workers, psychiatrists and mental health therapists, occasionally supervise the classrooms and would stop by throughout the day to check on the progress of care receivers.

We found five challenges of providing integrated care: the lack of real-time data, data consistency and data detail affect directly the degree of how care team members reflect and share information about care receivers' performance and progress, creating difficult challenges to achieve a successful collaborative reflection between providers and care receivers and challenges in sharing care receivers' information between internal and external care team members.

Real-time

Providers have difficulty maintaining records in real-time because they are concerned with the safety and wellbeing of the care receivers under their responsibility. In a healthcare environment such as a school, several behavioral crises could happen during the day (*e.g.*, a care receiver gets frustrated and leaves the classroom). We observed that several times paper records were left behind for hours at a time. Providers would not record data until later in the day, forcing them to rely on their memory of events and record summaries rather than accurate, specific data (*e.g.*, exact time or duration).

The care team and the recording instruments also move through different locations, making it challenging to record data in real-time. Activities throughout the school day are distributed across different locations (*e.g.*, classroom, cafeteria, gym, and music room). Providers are even busier with providing behavioral intervention during transitions and have an even harder time with writing down data while escorting care receivers down a hallway to another room. Providers tended to bring data sheets with them in a clipboard under their arm, and record any behaviors that occurred once they reach their destination.

Consistency

Providers manually recorded data throughout a school day, and did not use specific, uniform rubrics or codes. People, locations, activities, and types of data sheets changed many times throughout one day. Different people collected data in different situations. These sources of variance increased the complexity of recording consistent data about care receivers. In both classrooms, data collection is based on a behavioral intervention consisting of several behavioral categories (*e.g.*, voice control, task completion). We realized that there was no consistency in the behavioral intervention program used; one classroom added points in each behavioral category, when the other classroom would remove points if a disruptive behavior happens (*e.g.*, physical aggression).

Providers also lost the data sheets because of transitions and the high need for mobility. Providers need to start over with the record keeping activity, losing the existing data and recover only the information that is in their minds. In addition, when care receivers move from one location to other, providers not always carry the data sheets with them and as a consequence, important information about care receivers' behavior is lost.

Detail

Providers do not have enough time to write details of care receivers' behavioral information. They concentrate on recording points in the data sheets for each care receiver. When something in the classroom happens with a specific care receiver, providers need to look for this specific care receiver's data sheet, making time a crucial factor in writing details about his/her behavior (due to the need for activities in the classroom to continue with as little disruption as possible). In addition, the data sheets that providers use are designed to record points and they do not have enough space to write a behavior's contextual details.

Reflection

Reflection among the care team occurs informally, most of the time with the information that is in providers' minds and usually at the end of the school day. Also, when something to discuss of a particular care receiver emerges in the care team (*e.g.*, an illness), most of the time the record keeping instruments are not available as they transit between different physical locations during the school day. In addition, providers do not have files with historical data sheets (*e.g.*, last month data sheets) for each care receiver. They do not review the past data sheets to have a better understanding of the follow-up of care receivers' behavior.

Effective self-reflection by care receivers is not currently facilitated via existing data management practices. This kind of reflection only happens when a provider (*i.e.*, social worker) reviews the signed data sheets of each care receiver at the beginning of the day. There is no space for providers to go through the data sheets reflecting care receivers' behavior with them. On the other hand, data sheets are commonly misplaced by providers, unconsciously giving direct access care receivers to them. We observed several cases when different care receivers found the data sheets, looked their points and became upset by the amount of points they had, acting with a disruptive behavior such as breaking down the paper and throwing the paper to the garbage.

Sharing

We found a lack of two-way communication in sharing care receivers' information between internal and external care team members. Internal care team members are those who provide care inside the healthcare environment (e.g., therapists, psychologists, special education teachers, social workers). External care team members are those that are external to the healthcare environment but they are related to the care receivers as they are responsible for exposing them to the appropriate intervention (e.g., parents, tutors or family members). External care team members ask for care receivers' performance to providers in person, when they go to pick up care receivers at the end of the school day. Formally, there is no way of sharing information from external to internal care team members. External care team members expressed that most of the time they do not have enough information to effectively reiterate things at home. When care team members receive information about the care receiver, most of the time is about negative behaviors. In addition, when the external care team members hear about a negative behavior of their care receivers, they would like to have access to all the data that supports the comments of the providers.

Design principles for supporting integrated care

In this section, we summarize the design principles that resulted from our research process, and were validated through a three-year deployment study with a novel HIT system, Lilypad.

Real-time. HIT should enable healthcare providers to record and access data in real-time, in such way that all the care team members can access data at the moment the data are recorded from different devices. HIT must also provide mechanisms that facilitate care team members to collaboratively record data in real-time. For example, having predetermined information such as profiles of each care receiver, and automatically generating date and time of when records are being generated. This predetermined information should be configured by the care team members; so that they can decide what information could facilitate the process of data recording in real time.

Consistency. HIT should enable care team members to create standard formats, rubrics or codes from a configuration panel to maintain consistency in the collected data. In this way, the data will be stored following the same format regardless of the team member who records the data. Likewise, data should be stored on a cloud-preferred server, allowing the stored data to be available for all care team members to consult them.

Detail. HIT should provide mechanisms that can make it easier for providers to record care receivers' details without investing too much time (e.g., enable to record voice notes and having predefined fields to record details). Also, the interface design of the HIT has to provide a specific space to write care receivers' details, without losing data consistency. In addition, the HIT should provide a search tool to easily find the care receiver whom the provider wants to record details.

Reflection. HIT should promote reflection in three different ways: (1) *Care team reflection.* HIT should enable providers to record what happened in a particular situation and add a label or category to that situation (e.g., severe disruptive behavior). Other providers might receive notifications about the situation to provide support or suggestions. HIT should store historical files of each care receiver in a cloud-based server. HIT can use analytics (e.g., data mining) to predict behaviors of care receivers, it can learn from care receivers and provide suggestions about intervention or alerts about a specific care receiver's behavior that needs special attention. (2) *Providers to care receivers' reflection.* HIT should have an interface that providers could use to reflect on the information with care receivers. Providers should decide what information they want to show to care receivers in order to enhance reflection on care receivers' information (e.g., use simple graphs or language to show positive and negative behaviors through a day or week). (3) *Care receivers' self-reflection.* HIT should enable providers to maintain privacy in terms of the recorded data. Care receivers should not be able to see their stored data without the authorization of care team members. Instead of that, HIT might have a module to promote care receivers' self-reflection (e.g., to provide a common interactive ambient display).

Sharing. HIT should provide mechanisms to promote internal to external sharing and vice versa. (1) *Internal to external.* The HIT should provide a module to share information with external care team members (e.g., parents or tutors of the care receivers). This module should be managed by the internal care team members, as they would decide which information they want to share, as well as the kind of information they want to share (e.g., graphs, healthcare categories or tables). This HIT module should highlight positive and negative aspects of the care receivers' performance. (2) *External to internal.* The HIT should provide a module to enable external care team members to share information with internal care team members. For example, to have an online module (e.g., an app or a website) connected to the HIT where external care team members can share relevant information about care receivers.

The Lilypad system

The Lilypad system is a tablet-based electronic behavioral health record system that enables collaboration between care teams and supports integrated care. It consists of an iPad application and a web admin panel. The iPad application enables the care team to record behavioral data about care receivers. In the web admin panel, the care team can add or remove care receivers, edit care receivers' information, edit schedules, and select and personalize the type of data to record. Each care receiver is assigned to a class or group.

The web admin panel allows users to analyze individual and class-wide data. All the data is stored in a cloud-based server in such way that each care team member can record and access the data of the same care receiver at the same time from her own device using the iPad application or accessing to the web admin panel. The web admin panel enables the care team members to decide what type of data they want to record. For example, behavioral data based on a point system, categories for the behavioral intervention, comments, among others. For each category of the behavioral intervention (*e.g.*, task completion, voice control, and body control), the care team members can add comments to extend the detail of the recorded data.

Additionally, Lilypad has a feature to show care receivers' progress of the different behavioral categories. To promote sharing between internal to external care team members, Lilypad has a module where internal care team members can share care receivers' progress with external care team members such as parents or home care providers. Lilypad's module for sharing enables external care team members to record data about their care receivers' healthcare progress in order to share these data with internal care team members.

Lessons from Lilypad about HIT's role in an integrated care model

The transition from paper to Lilypad was a success¹⁴, and our deployment studied continued over three school years. Participating care teams have also expressed that they cannot imagine going back to their paper-based practices. Lilypad is now part of these teams' current practices.

Providers were able to record data in real-time during place transitions. For example, holding the tablet on top of a pile of folders and paper, one provider was able to record a care receiver's use of inappropriate language while verbally correcting the behavior as they stood in a line in the hallway. Lilypad enabled providers to record care receivers' data everywhere and every time, independently of the device and also independently of the provider. For example, there were occasions where a provider forgot her iPad, but she realized that she can use the iPad of another provider to record data. She was very excited to be able to use a different device to record data since she expressed that she could not lose a day of registering data, and also expressed that she did not want to return to paper-based practices.

Although, Lilypad enables customization of data recording, each data category defined for the care team could be also flexible. We found that the care team had sessions to discuss how the behavioral intervention would be applied (*e.g.*, give or take away points in the behavior categories, the maximum number of points, etc.). Lilypad helped the care team to agree and improve data consistency. They created the types of data in the admin panel agreeing. However, more work is required to understand what kind of mechanisms Lilypad should have to ensure that the type of data or the behavioral categories defined by the care team means the same for all the care team (level of agreement).

Providers expressed that with Lilypad they write more details than before (paper-based practices). Particularly, they wrote more incidents having the opportunity to add the start and end time for each incident. Additionally, they expressed that Lilypad enabled them to write comments about when a care receiver went to a cool-down room (a room where care receivers go when they had a strong behavior crisis), and keep a track of who was in the room and when. However, we found that we still need to work with the comments feature, as it is composed of text boxes; there are no mechanisms to validate words or the kind of recorded data. We found that because of the time, providers made typos and recorded incomplete comments using Lilypad. Further work is required to understand how Lilypad can achieve the right balance between enabling records to be malleable with individual behaviors and adaptive interventions, versus restricting the creation of records for consistent data.

Lilypad enabled providers to review the daily progress of the care receivers. Providers frequently used Lilypad to see who the care receiver with lowest points was and see what is happening with her. Additionally, the use of Lilypad increased the instruction/educational time as providers such as social worker did not need to interrupt the class to ask about the care receivers' progress. Instead, she reviewed care receivers' data from her office using the web admin panel without the need to ask other providers about care receivers' progress. In addition, we found that Lilypad helped providers to discuss care receivers' behaviors during breaks or after class. When a supervisor stopped at the classroom and asked about how the care receivers' behaviors are doing, providers used their iPad to

show what is going on with the care receivers' progress. We observed several times that in addition to the points earned in each behavioral category, providers also use the comments feature to update the supervisor about the class' progress.

Providers also used Lilypad to reflect on care receivers' progress during monthly care team meetings. However, the graphs automatically generated by Lilypad were not used extensively. In contrast, we found that providers used the Lilypad recorded data to create their own excel spreadsheets on monthly progress and then shared them with the other providers. This opens the opportunity for our research team to create a module that enables providers to personalize the data that they want to review and discuss (e.g., by month or by week, as well as by classroom or by care receiver). In addition, Lilypad promoted reflection between providers and care receivers. Providers were happy about that with Lilypad is easy to hide the points from the care receivers and avoid an inappropriate reflection. Instead, providers decided when to show the behavioral data to care receivers. In one of the schools, they scheduled times during the day to show care receivers their points through the iPad. In other school, providers used a projection display. On the other hand, we observed that the use of Lilypad promoted care receivers' self-reflection. Care receivers were more aware of their behavior as they self-corrected their behavior when they saw a provider took the iPad (e.g., care receivers quickly sat at their desks after saw a provider took the iPad).

Although the Lilypad version that was evaluated did not include a module for sharing data with external care team members, we found that providers used Lilypad to share care receivers' daily information with their parents. Providers sent a daily email to parents including the care receiver's name and data gathered through Lilypad (e.g., points by category, warnings, reminders, and comments). Further research is needed to investigate what mechanisms should provide Lilypad in order to share care receivers' information from internal to external care team members and vice versa.

Conclusion and future work

In this paper, we show the research process that we followed to design and evaluate a HIT for supporting integrated care. We hope that our design guidelines help other researchers to better design HIT aimed at supporting integrated care. As a future work, we plan to include the sharing module and consistency mechanisms to Lilypad and deploy this new version to investigate the impact of the proposed guidelines in supporting integrated care: real-time, consistency, detail, reflection and sharing.

References

- 1 Lawrence D. *From chaos to care: the promise of team-based medicine*. Perseus Pub, 2002.
- 2 Fitzpatrick G, Ellingsen G. *A review of 25 years of CSCW research in healthcare: Contributions, challenges and future agendas*. 2013 doi:10.1007/s10606-012-9168-0.
- 3 Harrison MI, Koppel R, Bar-Lev S. Unintended consequences of information technologies in health care -an interactive sociotechnical analysis. *J Am Med Informatics Assoc* 2007; **14**: 542–9.
- 4 Park SY, Pine K, Chen Y. Local-universality: designing EMR to support localized informal documentation practices. In: *CSCW '13*. ACM Press: New York, New York, USA, 2013, p 55.
- 5 Amir O, Gajos KZ, Swenson SM, Sanders LM. From Care Plans to Care Coordination : Opportunities for Computer Support of Teamwork in Complex Healthcare. 2015.
- 6 Marcu G, Dey AK, Kiesler S. Parent-driven use of wearable cameras for autism support. *UbiComp '12* 2012; : 401.
- 7 Marcu G, Dey A, Kiesler S. Designing for Collaborative Reflection. In: *UbiComp 2014*. 2014 doi:10.4108/icst.pervasivehealth.2014.254987.
- 8 Coddling RS. Preparing Educators to Use Curriculum-Based Measurement. In: *Handbook of Data-Based Decision Making in Education*. Routledge Handbooks Online, 2008.
- 9 Robson C. *Real world research: A resource for social scientists and practitioner-researchers*. 2nd Ed. Blackwell: Maldren, MA, 2002.
- 10 Guest G, MacQueen KM, Namey EE. *Applied thematic analysis*. Sage Publications, 2012.
- 11 Holtzblatt K, Wendell JB, Wood S. *Rapid Contextual Design: A How-to Guide to Key Techniques for User-Centered Design*. 2005.
- 12 Greenberg S, Carpendale S, Marquardt N, Buxton B. *Sketching User Experiences*. Morgan Kaufmann, Elsevier, 2012.
- 13 Strauss A, Corbin J. *Basics of Qualitative Research: Techniques and Procedures for developing grounded theory*. Second. SAGE Publications, 1998.
- 14 Nimley K, Marcu G. No longer in the Stone Age: A study of transition to electronic health records. In: *WISH*. 2016.