The Lilypad System
A Data Collection Tool to Support the Care of Individuals with Chronic Conditions

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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. The challenges of integrated care require innovation in health information technologies (HIT). In this demo, we present the Lilypad system, a novel HIT designed to support behavioral data management through a data collection application, a web admin panel, and care receiver modules.

CCS CONCEPTS
• Human-centered computing → User-centered design;  
• Applied computing → Health care information systems; Health informatics;

KEYWORDS
Health Information Technology, chronic conditions, data collection tools, integrated care

1 INTRODUCTION
Chronic conditions involve long-term care that requires coordination, which has differing complexities from the care required for acute illness or injury. 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 unique 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. However, HIT often fails to enhance collaboration and communication [2]. Novel HIT are needed to allow care teams to share data for monitoring progress and continuously improving care based on systematic assessment of what is and is not working [1]. For the integration of HIT to be successful, they need to blend seamlessly into existing practices and promote collaborative reflection among care team members [3].

We present a novel HIT system, Lilypad, which supports integrated care of individuals with chronic conditions. The Lilypad system has been deployed in a behavioral health setting, thus we describe its components within this context.

2 SYSTEM DESCRIPTION
Lilypad consists of three components: a tablet application that supports data collection activities; a website that supports customization of data collection as well as supervisory-level statistics; and two care receiver modules that allow for review and reflection on the data that has been collected.

Data Collection Application
The main component of the Lilypad system is a tablet application (Figure 1a), which is used by care providers to enhance data collection methods in four different ways. (1) Care providers record data in real-time on individual care receivers using customized behavior categories. Each care team member uses their own tablet to access a care receiver’s profile with real-time data. Thus, data collection can occur collaboratively and enable all members of the care team to review up-to-date data. (2) Data collected across care team members is time-stamped and stored following the same format, to promote consistency. (3) Care team members can record details about their care receivers through voice notes or text for every token logged. (4) Care providers can reflect on data in real-time using the ‘analyze’ tab. This allows in-situ data monitoring in line-graph format, including date range selection to quickly compare data over a desired period of time (Figure 1b).

Administration Panel for Customization
Dragonfly is the administration panel available in website form as part of the Lilypad system. Dragonfly is primarily used by care providers (e.g., supervisor level) and it allows the care team to customize the Lilypad system on an individual or group (e.g. classroom, care receivers, etc.) basis.
Figure 1: The Lilypad system’s tablet application: (a) customizable behavior counters and incident log where tokens, times, and comments get logged (b) analyze tab showing a daily view of tokens.

Dragonfly provides the care team with a more in-depth explanation of the care receivers’ data and allows them to decide which information they want to share with internal care team members (e.g., different care provider roles such as behavior analysts or social workers) and with external care team members (e.g., care receivers’ parents or tutors). Historical data of each care receiver are kept in a cloud-based server that can be accessed through Dragonfly, which automatically generates codes for recipients, behaviors, and time stamps all entries. A search tool helps care team members to easily access specific care receiver information. Dragonfly also allows care providers to tailor which information they want to share with the care receivers.

Modules for Care Receiver Reflection

The care receiver modules of the Lilypad system are designed for care receivers as the primary users, providing options for them to reflect on and collect their own behavioral data. The Lilypad system has two care receivers modules: (1) a wall-mounted display to allow care receivers (e.g., students) to keep track of their behavioral data (mostly positive tokens earned) in real-time [4]; (2) A smartwatch application to promote care receiver’s self-management of their behaviors, by having them collect their own data in individualized categories at the same time as the care team, who are using the tablet. This was created to help students with the transition from special to general education.

3 USER SCENARIO

We illustrate use of the Lilypad system with the following scenario: Miss Kim teaches in a special education classroom comprised of 12 students ranging from third to fifth grade, who have varying behavioral health needs. During an activity, Miss Kim hears Frankie making fun of another student’s reading skills. Miss Kim opens Lilypad on her tablet, and uses Frankie’s unique frequency counter for teasing to log a token. At Frankie’s next care team meeting, Miss Kim logs into Dragonfly, to reference Frankie’s data. During the discussion, she filters the data to only show tokens logged under his ‘teasing’ counter, and then generates a graph for the group to review together. Another one of Miss Kim’s students, Jill, is using the Smartwatch module of the Lilypad system to help her reflect on her behaviors. Jill is increasing her independents by logging her own behavioral tokens on the Smartwatch, while Miss Kim logs tokens in the same categories on her tablet. At the end of each period, the Lilypad system helps Jill compare her responses to Miss Kim’s, with the goal of increasing Jill’s self-monitoring skills by producing the same responses as Miss Kim.

REFERENCES