E-HEALTH AND ASSISTIVE TECHNOLOGY

Capitalizing on lived experience to design a smartphone app for everyday life

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Cognitive processes that fall under the umbrella of executive functions, such as problem solving, memory, planning, judgement and self-monitoring of performance, are integral in shaping performance of everyday life tasks. Even routine tasks such as grocery shopping, paying bills and taking medication require executive functions, which are often referred to as "integrative processes that guide goal-directed and purposeful behavior" (Cicerone, Levin, Malec, Stuss, & Whyte, 2006). Many health conditions such as brain injury, multiple sclerosis, autism spectrum disorder, attention deficit hyperactivty disorder and schizophrenia can cause executive functioning deficits. Identifying strategies to enable those living with executive dysfunction to engage in everyday life is of great interest to occupational therapists. Smartphone applications ("apps") may enable individuals with executive dysfunction to carry out everyday life tasks across multiple environments, increasing the potential for independent community participation (Evald, 2015; Kennedy et al., 2008).

Despite the proliferation of smartphone apps, little research has examined how an app can be used to enable occupational performance and engagement of individuals with executive dysfunction. Existing research has evaluated older technologies such as palm pilots and paging systems (e.g., Charters, Gillett, & Simpson, 2015; Chu, Brown, Harniss, Kautz, & Johnson, 2014). The capabilities of these older technologies (e.g., providing automated alerts/reminders) are now integrated into smartphone apps, which use updated hardware (e.g., different battery power, visual display systems) and can have a much broader range of features (e.g., synchronization of multiple calendars) due to internet connectivity.

For occupational therapists who would like to use smartphone apps as part of a cognitive intervention with clients, there is a lack of published research on how to apply this to practice. Currently, therapists must make decisions with limited evidence about what apps to choose and how to use them with a client. In the absence of formal research evidence, collaborating with and listening to individuals with lived experience can offer rich experiential knowledge about what works and what doesn't.

The intent of this article is to describe how an individual with lived experience of brain injury and executive dysfunction was able to apply his personal insights to design an app called Qcard to improve occupational performance and engagement. Although the app has yet to undergo clinical research, its unique design is based on the lived experiences of individuals with brain injury, as well as in how, through the design process, the app incorporated evidence-based cognitive strategies for managing executive dysfunction.

App development

After surviving a serious motor vehicle accident, Sergio Di Giovanni wanted to return to his pre-accident life, which included a wife, children, and a successful business, yet he experienced executive dysfunction that made this difficult. His goal was to create a comprehensive and user-friendly life management smartphone app.

During Sergio's rehabilitation, his occupational therapist recommended strategies to compensate for executive functioning and memory deficits, including using a daytimer to keep track of appointments and then setting alarms prompting him to check the daytimer each hour. Yet, Sergio found that none of these strategies worked; he was then motivated to design an app that would work for him.

"To use these aids with any success, they require your executive functioning to be working at full capacity. It was too error prone. There was no way I could actually run my life on [them]. Sticky notes, whiteboards, daytimers—I'd lose the daytimer, wouldn't have paper, or I'd put a note in my pocket and never see it again," Sergio explained. "I really needed a system I could depend on."

In 2007, the iPhone® was released and Sergio was able to have one covered through his motor vehicle insurance as an assistive

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device. He was hopeful that it would move the pen and paper strategies into a portable system he could easily use across environments. Although there were some smartphone apps available at the time, he did not find any that were suitable for his varied everyday life tasks.

Sergio, a software developer and entrepreneur who had been coding computer games since the age of 10, began to analyze why the available apps were not helping him. He identified that calendar apps did not account for the multiple steps required to complete most tasks, meaning that he often failed to follow tasks through to completion despite receiving a reminder. Sergio also discovered the need for a more personalized app that allowed the user to set and control the timing and content of task reminders. With support from others, Sergio began designing an app with multiple functions that would solve these pitfalls.

Moving from a concept to a real-world smartphone app

Sergio reached out to the Ontario Brain Injury Association and the Ontario Neurotrauma Foundation in 2011 for support to develop an app. Both organizations saw the merit in using lived experience in designing an app and he proceeded to interview other individuals with acquired brain injury, finding that they had experienced similar difficulties using their smartphones as an assistive technology. "They pointed to the exact same issues I was complaining about—I felt I was fixing the right things."

Designing an app and then starting his own company provided Sergio with the opportunity to resume productive and meaningful life roles. It also required him to consider what cognitive strategies were most helpful for his own recovery. "This is more than just a company that's filling a gap in the market," Sergio has said. "For me, this has real meaning."

Sergio's main goal was to create an app to organize and manage activities of daily living, compensating for difficulties he experienced due to executive dysfunction. A user can create a "cue card" for any activity he or she needs to carry out. The app can then serve as a mobile calendar allowing individuals to view their schedules for the day/week/month and to receive reminders for when specific tasks need to be completed.

Three different types of "cue cards" allow users to personalize the tasks and reminders they receive: orange reminders, green guided tasks and blue appointments. *Reminders* are used to schedule simple, one-step tasks like "take your medication," "water the plants" or "pay bills." The Reminder cue cards support prospective memory, providing a timely cue while giving the user the flexibility to manage it in the moment. For instance, should an individual receive a reminder to take medications while out for dinner, the task can be indicated as delayed, ensuring that the individual receives another reminder to complete the task upon arriving home.

Guided Tasks are used to schedule multi-step activities, like doing laundry, cooking a meal or getting ready for work, which require a number of executive functions such as attention, self-monitoring and sequencing, as well as working and long-term memory (Foerester, Carbonne, & Schneider, 2014). The Guided Task cue cards facilitate planning, by breaking a complex task into smaller steps, as well as self-monitoring, as timely reminders are provided when each part of the task needs to be completed (e.g., loading and then unloading the laundry).

Appointments are used to schedule future events or appointments that have a target date/time, which may aid a user in initiating and adhering to necessary schedules and routines. An Appointment can be set well in advance to help the user prepare. A separate travel time can also be set to help with timely arrival.

Design features

Several design features specifically address executive functioning deficits.

Colour-coding: Having three colours for cue cards helps to quickly orient a user to the activity he or she wants to access in the app without being distracting. Focusing on relevant information can be difficult for individuals with executive dysfunction.

"When writing down information or adding it to the native [iPhone®] calendar, everything looks the same," Sergio explained. "Same colour, same text. This means I [had] to re-read every line, every time I look at it, to distinguish priorities and what needs to be done now or later. It was unnecessary and overloading."

Current date and time: Having the current date and time always visible at the top of the user interface is key to supporting orientation and planning. When the app is opened, the user views the colour-coded cue cards for the current day from top to bottom. By swiping up, the user can scroll through future days. The calendar reads "today" and "tomorrow" before switching to month/day/year format (e.g., September 7, 2016).

"I can't find the words to describe it, but the concept of time is just not the same after the injury—there is a disconnect. For me, there's no difference between tomorrow or next week. It's just not there anymore."

Repeated reminder alerts: Difficulty with prospective memory, or the ability to remember to do something in the future, is another challenge experienced by many individuals with brain injury. Prospective memory is particularly complex, involving many executive functions (e.g., working memory, planning and flexibility upon disruption of an ongoing activity). Sergio's experience was that receiving one reminder alert to do something was not enough. It would easily get dismissed or forgotten, which resulted in things never getting done. To prevent this from happening, he programmed the app to repeatedly notify a user of overdue reminders until they are rescheduled, marked as complete, or deleted.

Support for families and care circles: Family members can send, manage and track each other's tasks in Qcard, reducing the caregiver stresses that come with supporting a member living with executive dysfunction. Sergio relates that this feature in particular decreased strain in his relationship with his wife. "Now I actually follow through and take out the chicken to thaw for dinner when she asks." An automatic message is sent back to the family member once the task has been completed.

The future of assistive technology

In keeping pace with technology's capabilities and in response to user feedback, Sergio is working on several additions to the app that may be of interest to occupational therapists. For instance, he is currently speaking with occupational therapists about creating an "OT Dashboard" that will contain a database of commonly used cue cards (e.g., doing laundry, grocery shopping, paying bills, arranging medical appointments). Therapists would be able to select and individualize cue cards and send them to their clients remotely. In addition, graphs of how a client uses the app (e.g., a decrease in the average number of reminder alerts used before engaging in a task) could be used to help a client visualize his or her rehabilitation progress.

Although this app aligns with client perspectives on the types of cognitive supports that are reported as helpful, the limitations of smartphone technology, such as accessibility, reliability and maintenance requirements, also apply to this app's design (Chu et al., 2014). Many of the features discussed in this article were designed to create a user-friendly app, but basic skills in using a smartphone are still required of users.

As mentioned previously, evidence-based guidance on *how* to implement smartphone apps as cognitive supports is limited. Some techniques, such as errorless learning and vanishing cues, have been utilized for teaching technology to individuals with executive or memory deficits (see Charters et al., 2015), yet *how* and *when* an occupational therapist should intervene using smartphone apps with clients with executive dysfunction requires further evaluation. It is evident therefore that as smartphones and mobile technology become more integrated into our everyday life, occupational therapists are positioned to have an important role in how these devices and software are used, designed and researched.

This article describes how engaging in a collaborative design process led by an individual with lived experience created an end product that filled a niche in the current market. By incorporating evidence-based cognitive strategies and focusing on the everyday needs of people with executive dysfunction, smartphone apps can be developed to effectively address the needs of device users. As the technological revolution continues, capitalizing on end users' lived experience may not only lead to the creation of more responsive apps for everyday life, but may also provide therapeutic benefit through meaningful occupation for those who engage in the design process.

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