A digital support device designed to help family caregivers coordinate, communicate, and plan the care of people with brain injury

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Motivation
Primary caregivers of brain injury survivors must coordinate not only their own schedules, but the schedules of other secondary family caregivers as well.

Approach
We conducted interviews and observations of 3 families caring for individuals with brain injuries. Based on our data, we created 2 prototype systems and conducted formative evaluations using expert and heuristic review.

Usability Tests
We conducted usability tests of our 2 prototypes with 2 primary caregivers and 2 case managers. Questionnaires and interviews were administered to evaluate usefulness and usability of the prototype systems.

Participants
Participants were selected from cases managed at COTA Health in Toronto. In total, 3 primary caregivers participated in the interviews:

1. A middle-aged married woman caring for her children and mother, who suffered brain injury.
2. A middle-aged married woman who works full-time in addition to caring for her husband with brain injury.
3. A middle-aged married woman who works full-time, cares for her children, and also cares for her husband with brain injury.

Results
Based on observations of caregivers using the prototypes, we generated the following set of design guidelines for building systems for caregivers and their families:

1. Coordination occurs most frequently in common areas (all 3 families referenced the kitchen). For this reason, support systems should be available in prominent areas like the kitchen.
2. Because caregiving support is distributed among many people (including neighbors, extended family, friends, and coworkers), it is important for availability information for possible caregivers to be included in the system. The system should support shared scheduling of care.
3. All 3 families noted that whiteboards are the preferred mode of asynchronous communication. System designers should either provide similar functionality or support the presence of an actual whiteboard.
4. Caregivers often rely on health and community service directories. The system should support integration of community-supplied resources.
5. Care recipients take an active role in the coordination of their own care. For this reason, the system must be accessible to individuals with cognitive, physical, and/or sensory impairments.
6. As the care recipient recovers, he or she can begin to use more advanced portions of the system that would normally be reserved for caregivers. Likewise, if a caregiver’s role changes from a primary support position to a secondary one, they need fewer details about the daily activities involved in giving care. Dynamic profiles for each user should be available in order to hide or display pertinent information according to ability.

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