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Social connectivity for stroke patients in a hospitalized environment

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Abstract
In this paper we present the user centered process and evaluation of a social connectivity service for stroke patients, their loved ones and staff. In line with previous studies we show that interpersonal connectivity and "connectivity to the world" is an unmet need for stroke patients. Patients experience face-to-face visits of close loved ones, the most important form of social activity, as suboptimal and there is a need to receive personal pictures and "get-well" cards from loved ones. We developed a Social Connectivity based on three iterations of contextual inquiry, low- and high fidelity prototyping involving 83 stroke patients, family and staff. This was done in four hospitals in the Netherlands, Belgium, and Denmark to allow cross-cultural validation. The system aims to improve the patient social interaction with their loved ones in two main ways: make planning of the face-to-face visits more optimal and by providing loved ones with additional electronic means like sending pictures, e-cards, and drawings to show their compassion and enable them to actively contribute to the healing process of the patient. This application supports the coordination of the visiting process of loved ones and stroke patients. This reduces the need for staff to coordinate, manage and correct expectations and behaviour of visitors, and streamlines the visiting process for patients and family. The results show that patients, family and staff were enthusiastic about the applications, and further refinements are suggested.

Keywords: stroke, social connectivity, user evaluation, user-centered design

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Introduction

Every year, 15 million people worldwide have a stroke with approximately one third of these dying due to the attack and one third remaining permanently disabled (Mackay & Mensah 2004). Stroke patients suffer from a stroke which is the brain equivalent of a heart attack. Blood must flow to and through the brain for it to function. If its flow is obstructed, areas of the brain can lose oxygen supply, causing damage. A stroke has a tremendous impact on the life of patients and their families. A stroke can cause multiple cognitive, motor and emotional deficits. The majority of stroke survivors require rehabilitation (Goldstein *et al,* 2006). Previous studies indicated that interpersonal connectivity and "connectivity to the world" is an unmet need for hospitalized stroke patients (Daemen *et al,* 2014). Interpersonal connectivity is defined as the need for stroke patients to stay connected to their loved ones. "Connectivity to the world" reflects the patient's need for being informed with what is going on in the world such as world news or the score of their soccer team. This paper presents connectivity needs of stroke patients and their loved ones in a hospital setting and the design of a tool that supports these needs.

Research methods

The research was conducted through an iterative user centered design process (Nielsen 1992; Hevner *et al,* 2008) of designing and evaluating with patients, loved-ones and health-care specialists. First contextual inquiries were conducted to investigate the connectivity needs of stroke patients and their loved ones in a hospital setting. Future users were confronted with storyboards of eight social connectivity concepts. Next medium-fidelity prototypes were developed and validated and finally a high-fidelity prototype was developed (Figure 1).

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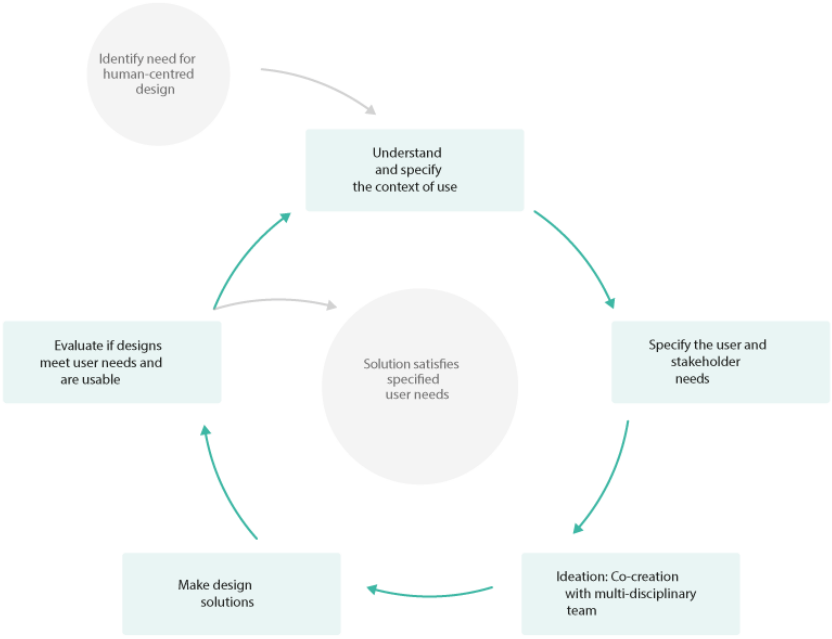

Figure 1 User centered design process

Iteration 1 – Contextual inquiry

Research method

First a high-level contextual inquiry was performed to map current social interaction patterns. (Goodman *et al,* 2012; Gulliksen *et al,* 2003; Johnson *et al,* 2005; Martin & Hanington 2012). Insights were gathered through semi-structured interviews with stroke patients admitted to the neurology department, their family, and staff members in one Dutch and one Belgian hospital (Table 1). An open-ended interview technique was used considering that little was known a-priori about the connectivity needs of the stroke patient. However, a list of predefined probes was used to initiate the conversation whenever necessary.

Table 1 Participants social connectivity research

Iteration / Users	*Iteration 1* Contextual inquiry	*Iteration 2* Storyboard	*Iteration 3* Low-fidelity prototype	**Total**
Patients	13	7	9	29
Loved ones	6	4	5	15
Nurses	9	4	8	21
Therapists	4	6	4	14
Neurologists	1	3	/	4

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Findings

The first set of interviews revealed that stroke patients have different connectivity needs depending on how socially and emotionally close they feel to the different friends and family members (Figure 2). Patients typically only want to be visited by a small group of very close loved ones at the right time of the day since they have little energy, need time to emotionally cope with their sudden medical condition, and often feel embarrassed sharing this with others. At this stage, "very close" loved ones can be as limited as the spouse only, or a larger group, typically including (grand) children, closest siblings or friends.

Loved ones often have limited understanding of the extremely fragile cognitive, emotional and physical condition of patients and therefore do not realize that their visits can be albeit pleasant, also exhausting for patients. This requires staff to coordinate, manage and correct expectations and behaviour of visitors, and streamline the visiting process for patients and family. At the same time close loved ones coordinate visits while having insufficient insight into the daily schedule of the patient. Consequently they visit the patient while therapy or imaging sessions are planned. Patients in turn find it difficult to express to the visitors that "it is enough". Currently, it depends on attentive nurses to step in when they think that visitor presence interferes with the patients' recovery. Patients, loved ones, and staff would benefit from better visit coordination and tailored information.

Often stroke patients prefer not to be visited by people less socially and emotionally close to them. However, they do appreciate getting "get-well-soon" cards which also are a means for less close loved ones to fulfil their own need of showing compassion to the patient. Staff indicate positive motivational effects on patients who receive get-well cards, drawings and personal pictures from loved ones (with certain scenes, persons or activities in the picture).

The most distant group of "acquaintances" is currently typically not informed that the patient is hospitalized at all. Hence, the future solution presented should not change the accepted social dynamics by providing acquaintances quick access to the patient.

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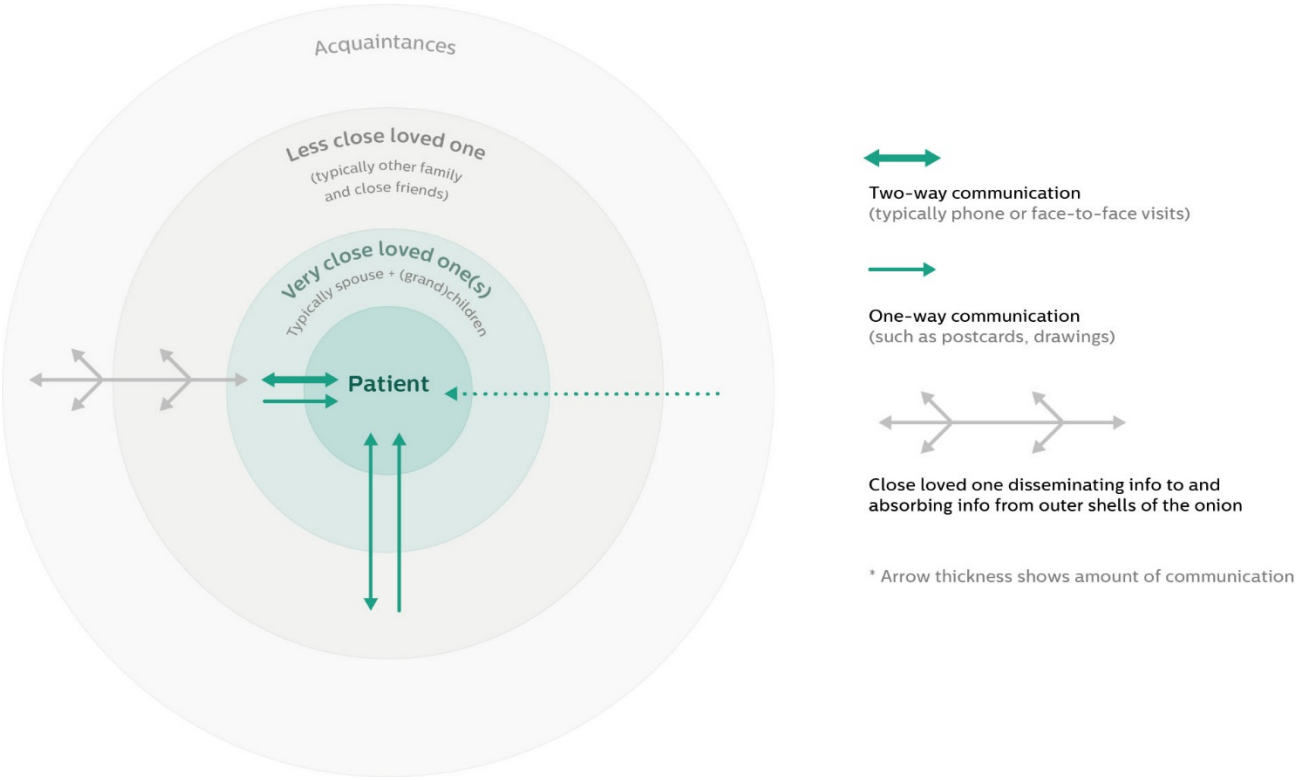

Figure 2 Union model

Iteration 2 – Storyboard evaluation

Ideation & Creation

Based on these insights a brainstorm session took place. Four concept solutions were created: optimizing visits of close loved ones by providing visiting advice and an agenda, monitoring time and sound during visiting hours, providing tailored healing stimuli. These were visualized in storyboards (see Figure 3).

Evaluation method

The storyboards were evaluated using a cognitive walkthrough approach with patients, loved ones, nurses, therapists and neurologists in three neurology wards in the Netherlands, Belgium and Denmark (see Table 1). The goal of the session was to identify the most useful concepts and improvement points from a multi-stakeholder perspective.

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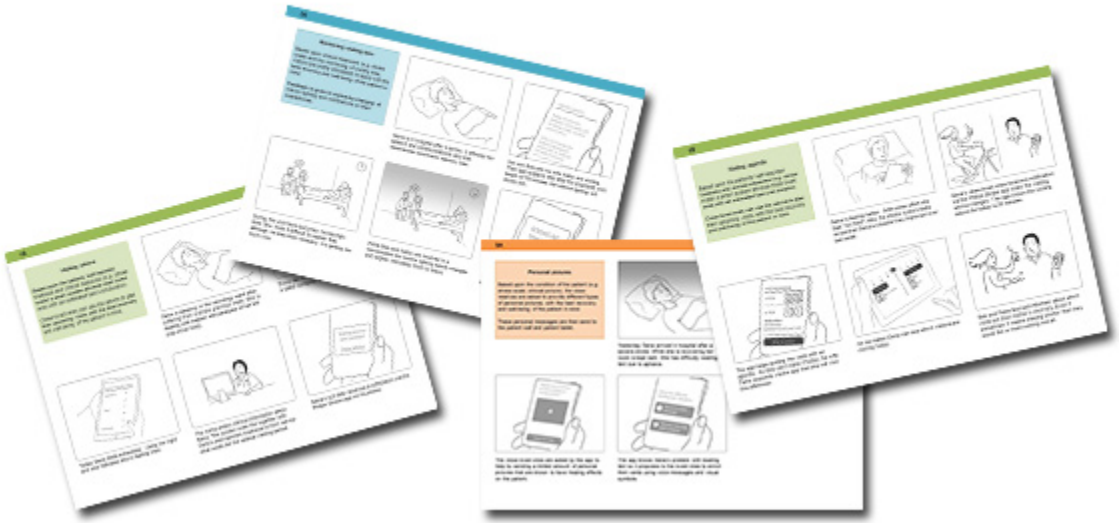

Figure 3 Storyboards based on the following insights: face-to-face social contact, indirect social contact and providing tailored information.

Findings

From the four concepts two were seen as worth investigating further by patients, loved ones, and staff. They facilitate the two inner layers of the social union (Figure 2) and are described below.

Optimizing visits of close loved ones by providing visiting advice and an agenda.

Loved ones and patients currently are provided with an overload of generic information about stroke that is not tailored to their specific case. Loved ones and patients cannot digest this information in the sudden emotional roller-coaster of acute stroke (Eames *et al,*, 2010). Stroke symptoms differ considerably between patients depending on their specific neurological damage. Our hypothesis is that providing loved ones with reliable disease information tailored to the patient-specific stroke symptoms and which is available anywhere to close loved ones selected by the patient will increase their understanding of the fragile state and communication disabilities of the patient. This allows loved ones to sense when patients are tired, and tailor their communication pattern to the stroke patient suffering from aphasia or other communication impairments through communication advice.

Providing a transparent day schedule of the patient allows loved ones to time their visits well. This allows patients to energize themselves before loved ones arrive. It enables patients and close loved ones to optimize and take control over their visits, with little need for staff to streamline this. In sum, this solution enables better self-regulation of the social interaction between patient and loved ones, which was appreciated by them as well as staff through reduced workload and patient satisfaction.

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Providing tailored healing stimuli (pictures, e-cards, tailored messages and information)

Our hypothesis for the second part of the concept was to enable tailored exchange of electronic pictures, cards and messages to trigger memory recall with personal stimuli and as a form of rehab triggering stimulation of affected neurons (Cicerone *et al,* 2011). Though this is mostly possible with any smartphone, the UI is not tailored to meet either stroke patients' disabilities or the relatively elderly population of close loved ones. Staff confirmed that pictures would be beneficial for the patient: it would trigger memory, could make the environment more familiar and could help the nurse to test the patient's condition. Also therapists indicated that they would use the pictures during their therapy, for example pictures could be beneficial to practice words during speech therapy. Patients appreciate receiving pictures from family members that they can also use for small talk with staff and other patients.

Iteration 3 – Usability test prototypes

Ideation & Creation

Based on the input of iteration two, a social connectivity system was created with three user interfaces: a Patient UI, a Family UI, and a Nurse UI (see Figure 4). This application supports the coordination of the visiting process of loved ones and stroke patients. This reduces the need for staff to coordinate, manage and correct expectations and behaviour of visitors, and streamlines the visiting process for patients and family. The staff UI provides an overview of the agenda and a short overview of a patient's medical record. It also allows loved ones to send digital pictures, e-cards, and drawings to show their compassion and enable them to contribute actively to the healing process of the patient.

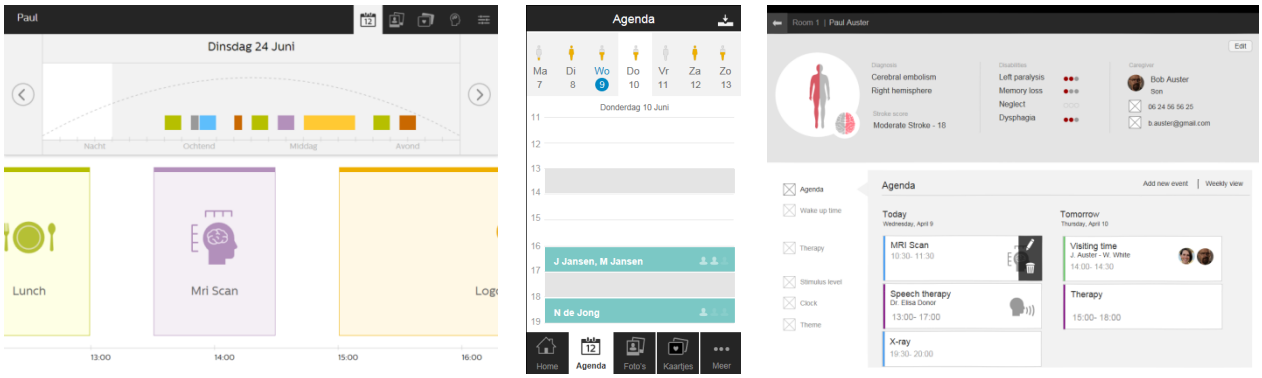

Figure 4 Medium fidelity (patient app, family app) and low fidelity (staff app) prototypes

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Evaluation method

Feedback on these concepts was gathered in this third iteration in two Danish and one Dutch hospital using a user test with think-aloud protocol (Nielsen, 1992). The aim of the usability test was to gather very early feedback on the usability and usefulness of the design concepts. Patients, family, and nurses performed a set of realistic user tasks as defined in the test script with their own UI on an iPad. Their interaction with the UI was observed and additional post-test questions were asked about ease of use and comprehension of information on the UI.

Findings

The results show that patients, family and staff were enthusiastic about the applications, but refinements had to be made. In general patients believe the patient UI would be useful and desirable. Loved ones believe the family UI would be useful. Some relatives express that they already manage the patient's visits, bring photos, either by text email or physically. Staff expressed worries that families would use the agenda as "evidence" towards the staff: "the agenda says that my dad should have been in the MR scanner by now". It is therefore important to make clear that the timing of activities is approximate.

UI recommendations

Patient UI.

General. The results of the usability test differ considerably per stroke patient. Patients' medical conditions vary greatly from patient to patient, and from day to day. Some patients find everything easy and understandable, where others are at a complete loss of what to do. It is therefore important to take into account in the next iteration that the UIs can be adaptable to the condition of the patient.

Physical limitations. Stroke patients have to cope with physical limitations due to paralysis. Often their coordination is affected and this leads to imprecise movements. Therefore we recommend using oversized icons, buttons and text without looking stigmatizing. In addition from a physical ergonomics point of view, the interaction with the tablet should be a "closed chain", that is, the whole interacting arm of the patient should be physically supported.

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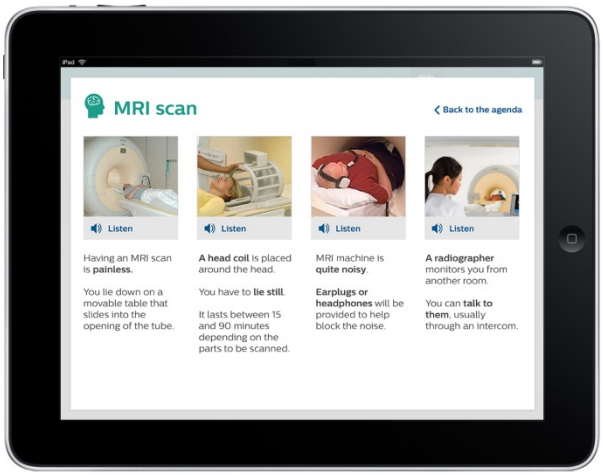

Figure 5 MRI scan information: Limiting the amount of information and using text, visuals and audio

Aphasia. Stroke patients often suffer from aphasia, a communication disorder. An aphasic person loses the ability to transfer his or her thoughts into words and sentences due to brain damage. Depending on the area and extent of the damage, someone suffering from aphasia may be able to speak but not write, or vice versa, understand more complex sentences than he or she can produce, or display any of a wide variety of other impairments in reading, writing, and comprehension. We therefore recommend using both icons and textual representation. In addition the visual representation is supported by other media such as audio (see Figure 5) allowing impaired patients to overcome limitations in visual working memory with auditory information (Baddeley & Hitch, 1974).

Cognition. Patients' medical conditions vary greatly from patient to patient, and from day to day. Ideally the UI would be based on the patient's condition and should be adaptable over the day or hospital stay of the patient. Patients often experience weakness and fatigue. We therefore recommend limiting the amount of information by for example segmenting information into parts (see Figure 5). The UI should also be easy to learn. The animations used and transitions should be slow. The text should be simple and short, for example one sentence as a paragraph. Finally we recommend that the level of navigation should not go deeper than two layers. Users should be able to go back to the main page easily.

Perception. Stroke patients suffer from perception problems. Often they have neglect, which is an attention disorder that prevents the patient from attending to stimuli on one side. The recommendation for the UI features is that the icons should be visually simple through use of a known metaphor combined with a solid background colour, so icons and text become clearer. For patients with neglect, an iPad format tablet is small enough to be positioned within the field of view. A tablet with a black border has better contrast with content then white tablet.

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Family UI.

Family members, more specifically spouses, are often elderly people. We therefore recommend the UI to be simple and use familiar navigation to make it easy to learn. Also make use of use a simple language, by avoiding complex sentences and explain medical jargon. Especially for elderly users, make sure that navigational elements are clear to understand. Instead of "Confirm", use "Yes, I accept the invite". In addition family members are often worried and under a lot of stress. Therefore we recommend using a reassuring tone of voice. We recommend giving guidance, education and support text with instructional illustration.

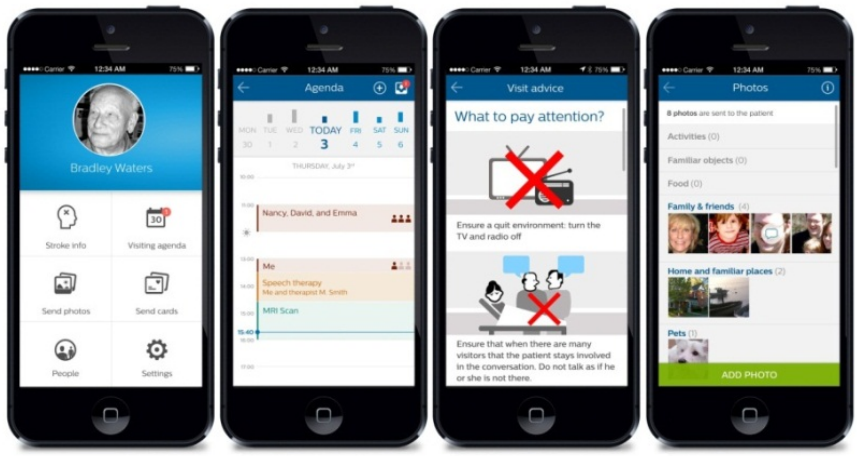

Figure 6 Loved One's app with a stroke information function, agenda function, information function and uploading pictures function

Staff UI.

The staff UI (Figure 7) should not interfere with the workflow. We therefore recommend highlighting important events in the agenda by using icons and colour. In addition we learned that showing a short overview of a patient's medical record was not desired. The hospitals have their own electronic patient record and nurses believed this was an unnecessary repetition.

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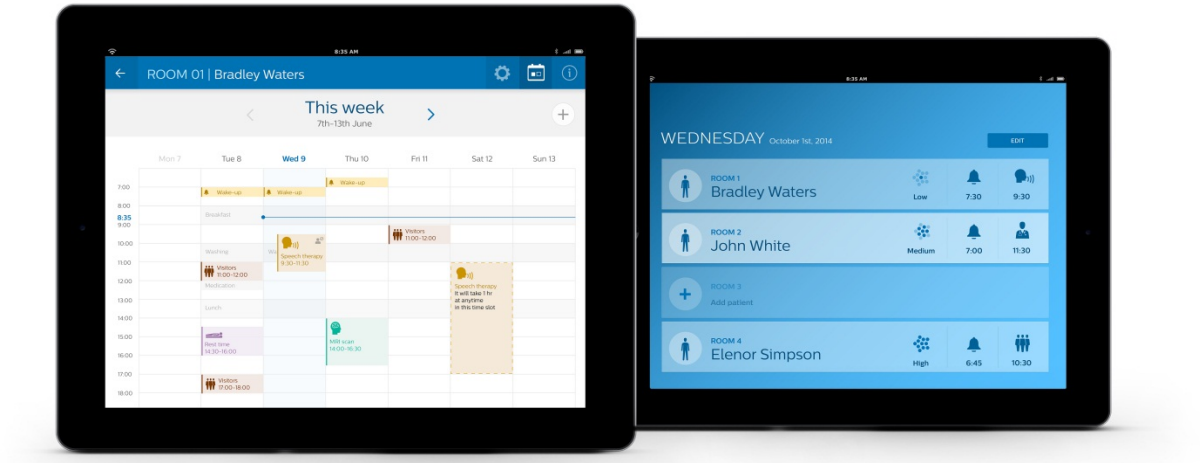

Figure 7 Staff app with an agenda function and overview function

Conclusion

Social connectivity is a need for stroke patients and their loved ones. The Social Connectivity system improves the patient social interaction with their loved ones in two main ways. It makes planning of the face-to-face visits more optimal and reduces coordination burden on close loved ones and staff. Also it provides loved ones with an additional electronic means (sending pictures, e-cards, and drawings) to show their compassion and enable them to actively contribute to the healing process of the patient. Based on the findings a high-fidelity prototype was created (Figure 6-8). An additional longitudinal field test where the prototype is given to potential users for a period of time is required to validate the high-fidelity prototype. This can demonstrate its actual value in a hospital setting.

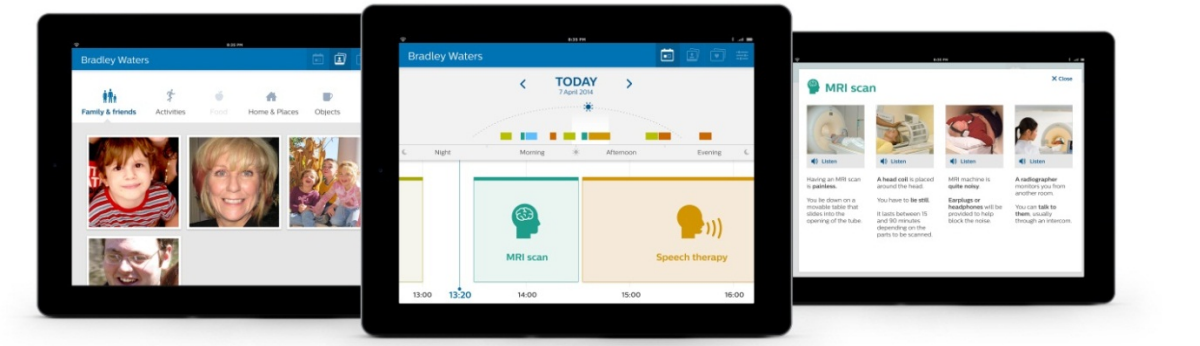

Figure 8 Patient app with agenda function, viewing pictures function and information function

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