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DObs

Dementia Observation

PROJECT REPORT

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1. Introduction

Behavioral symptoms in dementia, such as agitation and aggression, are common and distressing for caregivers and patients. It is estimated that 80% of residents of long-term care homes have dementia, and that 70% of these individuals will have behavioral problems, 30% severe. A basic principle of assessment of behavioral symptoms is to document the behavioral patterns over 24- hour periods, to help establish their frequency, severity, and any antecedents to the behaviors. A widely used tool for this is called the dementia observation system (DOS), which is paper-based, onerous, and difficult to discern patterns. The DOS typically notes behaviors at 30 minute intervals, which results in a significant oversight in behavior data collection. Furthermore, after the collection of the data, there is no computerized means to analyze it for patterns.

Given the predictions of growth in the population with dementia, more cost effective and efficient tools are needed to assess and treat behavioral issues. The goal is to develop a mobile app that would integrate information from nursing/caregiver observations with data from a wearable device on the observed resident with dementia. The process of behavior observation typically occurs over 24 hours, during a 5 -7 day period.

The first component would consist of an android based app, which would be accessed by the caregiver through a smartphone. The caregiver would be prompted to document patient behaviors on a regular schedule (every 15 – 30 minutes). The caregiver would choose from a selected list of typical behaviors, and then from a list of environmental contexts (from which the behaviors occur). An additional feature would be the ability to add occurrences after the fact: (1) medications given at times when a person's behaviors escalate, so as to identify medication treatment needs, and (2) ability to enter aggressive episodes retroactively, as the caregiver staff would be otherwise occupied dealing with the aggressive person at the time and therefore not able to enter the information into the app. These features would include a timeline, which would then correctly enter the occurrence into the database.

The second component of the app would consist of a wearable device for the person with dementia. A wristband type device would be preferred, to prevent removal or accidentally being lost. This would need to be waterproof, so as to maintain being worn throughout the 24 hour day, including during bathing which is often a cause for agitation. Measurable data would focus on sleep cycles and motor agitation. Sleep cycles are often disrupted and at intervals in dementia patients, and essential to monitor with regard to medication and behavior patterns. Monitoring of changes in motor agitation is needed as it supplements the periodic data inputs from the caregivers and is a more accurate reflection of behavior change patterns. Another feature of the app, would be a process to be able to generate reports about these patterns that can be used to direct treatment or monitor response to treatment.

2. Overall Design

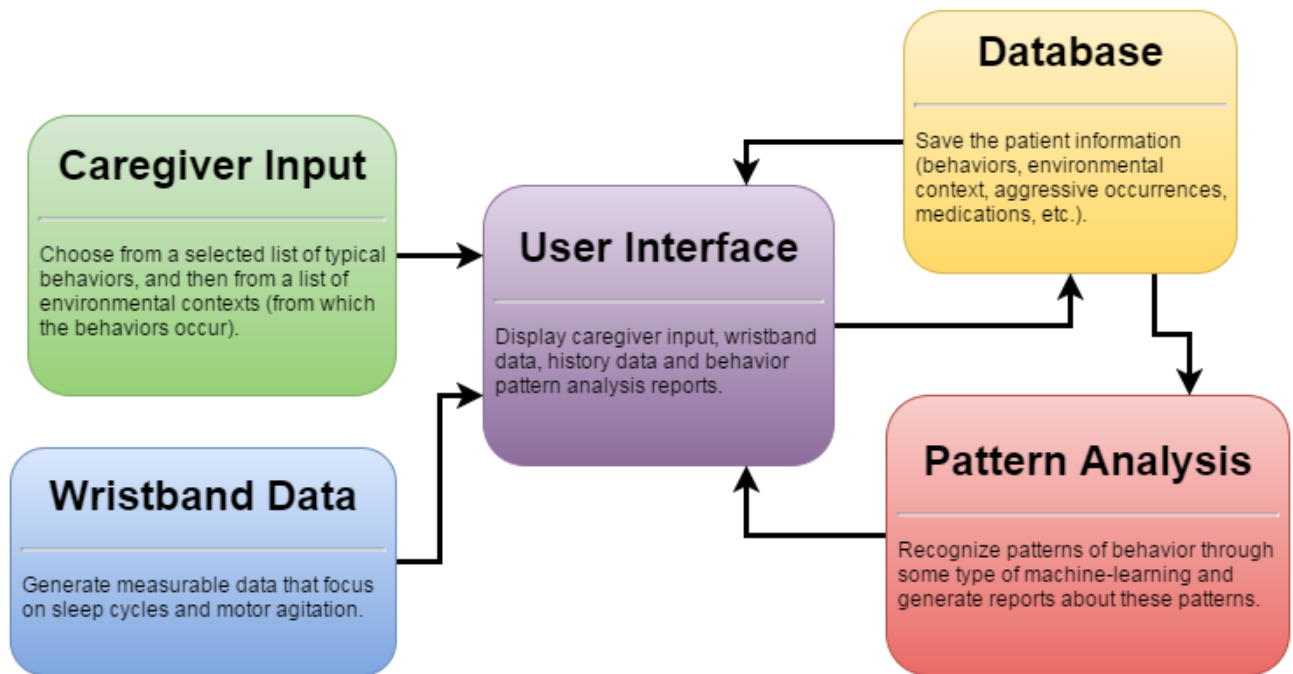


Figure 1. Block Diagram

●Caregiver Input:

Choose from a selected list of typical behaviors, and then from a list of environmental contexts(from which the behaviors occur).

●Wristband Data:

Generate measurable data that focus on sleep cycles and motor agitation.

●User Interface:

Display caregiver input, wristband data, history data and behavior pattern analysis reports.

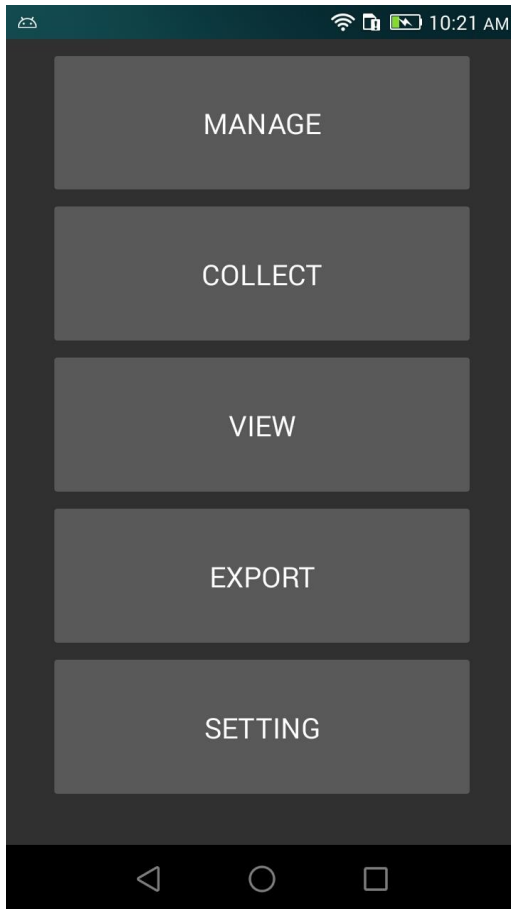
●Database:

Save the patient information(behaviors, environmental context, aggressive occurrences, medications, etc.).

●Pattern Analysis:

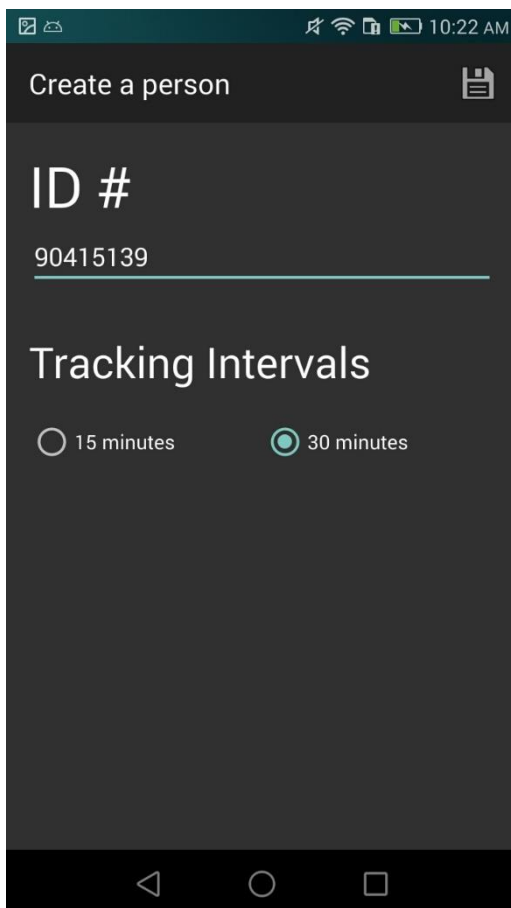
Recognize patterns of behavior and generate reports about these patterns.

3. Statement of Functionality



Main screen

Allows caregivers to choose one of the five functions (Manage, Collect, View, Export and Setting).



Create a profile

It would generate randomly an 8-digit ID number.

Specify the tracking interval, 15 minutes or 30 minutes.

Choose behaviors

Sleeping in chair ☐

Sleeping in bed ☒

Awake & calm ☒

Noisy ☐

Restless, pacing ☐

Aggressive-verbal ☒

Aggressive-physical ☐

Choose behaviors

There are 7 standard behaviors.

Choose several behaviors of the patient that the caregivers want to monitor.

Add new behaviors

throwing

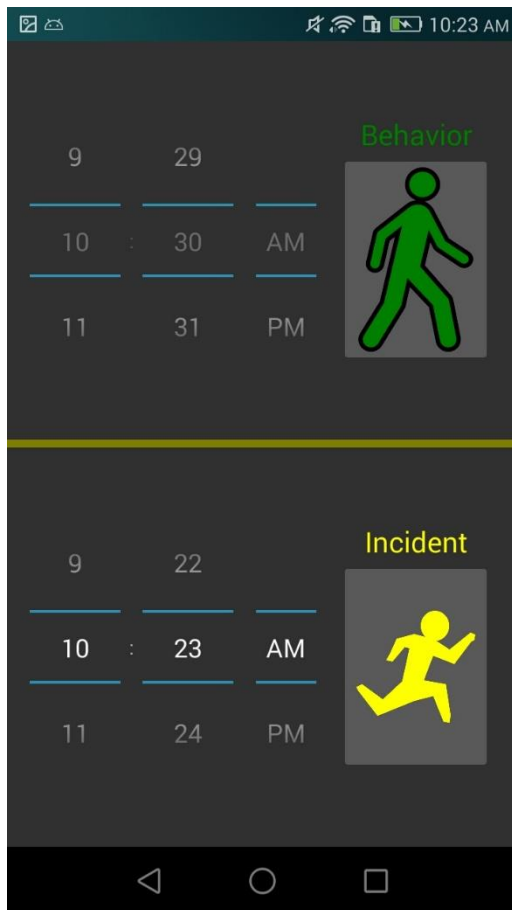
2. Enter new behavior

3. Enter new behavior

4. Enter new behavior

Add new behaviors

Other than the above 7 standard behaviors, the caregivers could add new behaviors, such as "throwing".



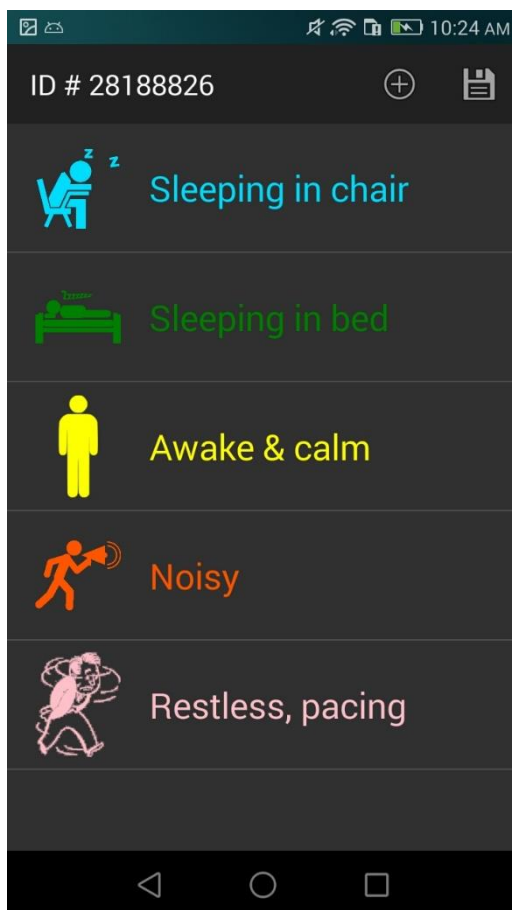
Collect function

On the top is to collect behaviors. Time is unchangeable (In order to accurately reflect). Time would be automatically set to a near interval, such as "10:30".

On the bottom is to collect incidents. Time is changeable (In order to input incidents retroactively).

Click green button to collect behaviors.

Click yellow button to collect incidents.




Select a behavior

Select one behavior of the patient.

The "Add" button to the left of "Save" button can lead to adding new monitoring behaviors in case current selection of tracking behaviors needs to be modified.

The "Save" button will save behavior records and jump to an interface indicating environment context.


Choose an environment: 

- noisy/loud ☐
- activities ☐
- music ☐
- cleaners/housekeeping ☐
- intrusive residents ☒
- crowded ☐
- visitors ☐
- care-dressing ☐
- bathing/shower ☐
- peri-care ☐

Select an environment

Here is a list of environments where a behavior may occur.

Click “Save” to store the record.

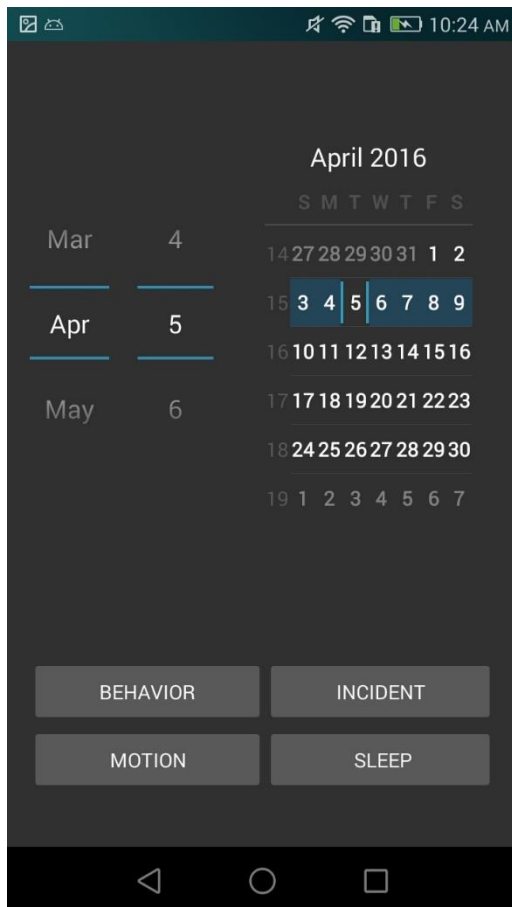
Create an incident 

Please indicate which happened:

- ☐ Fall
- ☒ PRN Medicine
- ☒ Aggressive Incident

Collect an incident

In the case of the caregiver catching sight of some incidents (e.g. fall, PRN medicine, aggressive incident) happening on the patient at a certain moment, she may need this functionality to keep a record of them.



View function

View records of “behavior”, “incident”, “motion” and “sleep patterns” on a specific day.

Apr 05 at 09:00 AM	Sleeping in chair	redirection
Apr 05 at 09:15 AM	Sleeping in bed	peri-care
Apr 05 at 09:30 AM	Noisy	music
Apr 05 at 09:45 AM	Sleeping in chair	crowded
Apr 05 at 10:00 AM	Awake & calm	quiet
Apr 05 at 10:15 AM	Sleeping in bed	mealtime
Apr 05 at 10:25 AM	<PRN> <Aggressive>	
Apr 05 at 10:30 AM	Restless, pacing	peri-care
Apr 05 at 10:45 AM	Noisy	peri-care
Apr 05 at 11:00 AM	Sleeping in bed	redirection
Apr 05 at 11:15 AM	Sleeping in bed	mealtime
Apr 05 at 11:30 AM	Sleeping in chair	bathing/shower
Apr 05 at 11:45 AM	Sleeping in bed	visitors
Apr 05 at 12:00 PM	Sleeping in chair	noisy/loud
Apr 05 at 12:15 PM	Sleeping in chair	redirection
Apr 05 at 12:30 PM	Sleeping in bed	other
Apr 05 at 12:45 PM	Noisy	redirection
Apr 05 at 01:00 PM	Restless, pacing	visitors
Apr 05 at 01:15 PM	Sleeping in bed	other
Apr 05 at 01:30 PM	Awake & calm	activities

View behaviors

View behaviors and the corresponding environmental context (input by caregivers) throughout a day.

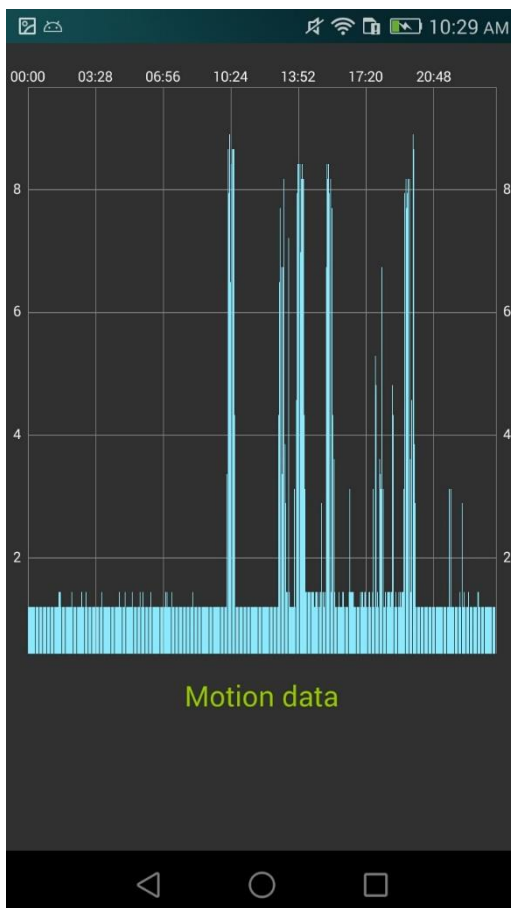
The first column denotes time line, the second behavior and the third environment.

Note that “incidents” also display on this screen among behaviors, following time sequence in the background of black.

Apr 05 at 02:25 AM	<Fall> <PRN>
Apr 05 at 06:23 AM	<Fall> <PRN>
Apr 05 at 07:23 AM	<Aggressive>
Apr 05 at 07:25 AM	<PRN> <Aggressive>
Apr 05 at 07:28 AM	<Fall> <PRN>
Apr 05 at 08:08 AM	<PRN> <Aggressive>
Apr 05 at 08:12 AM	<PRN> <Aggressive>
Apr 05 at 08:20 AM	<Fall> <PRN>
Apr 05 at 09:23 AM	<Fall> <PRN> <Aggressive>
Apr 05 at 10:25 AM	<PRN> <Aggressive>
Apr 05 at 10:29 AM	<PRN> <Aggressive>
Apr 05 at 10:33 AM	<PRN>
Apr 05 at 11:29 AM	<Fall> <PRN>
Apr 05 at 01:27 PM	<Fall> <PRN>
Apr 05 at 01:33 PM	<PRN> <Aggressive>
Apr 05 at 02:20 PM	<Fall>
Apr 05 at 02:28 PM	<Fall> <Aggressive>
Apr 05 at 03:33 PM	<Fall> <PRN>
Apr 05 at 05:37 PM	<PRN>

View incidents

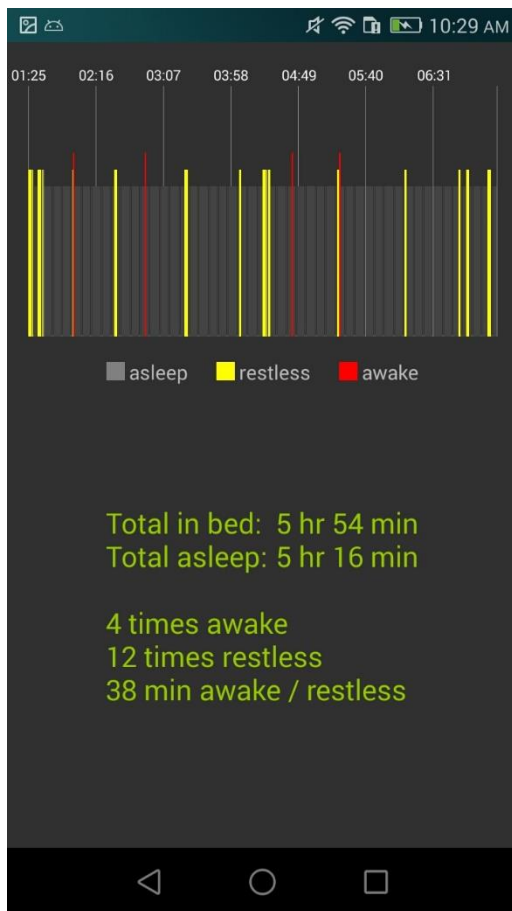
Here is a list of all the incidents occurred (input by caregivers), not just on a single data.



View motion

View motion records (tracked by wristband) minutely throughout a day. Through scaling, the chart can be detailed to each minute.

Long press the chart to save it to phone gallery.



View sleep

View sleeping cycle (tracked by wristband) throughout one night. Through scaling, the chart can be detailed to each minute. Note that the legends below may help to observe sleeping patterns.

Gray bar stands for “asleep”.
Yellow bar stands for “restless”.
Red bar stands for “awake”.

Export to excel

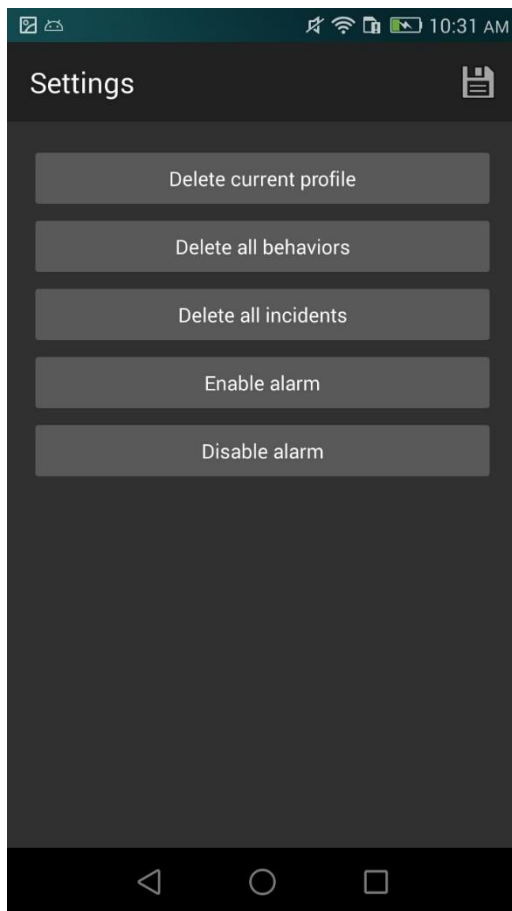
Select a period to export:

start date to end date

EXPORT CANCEL

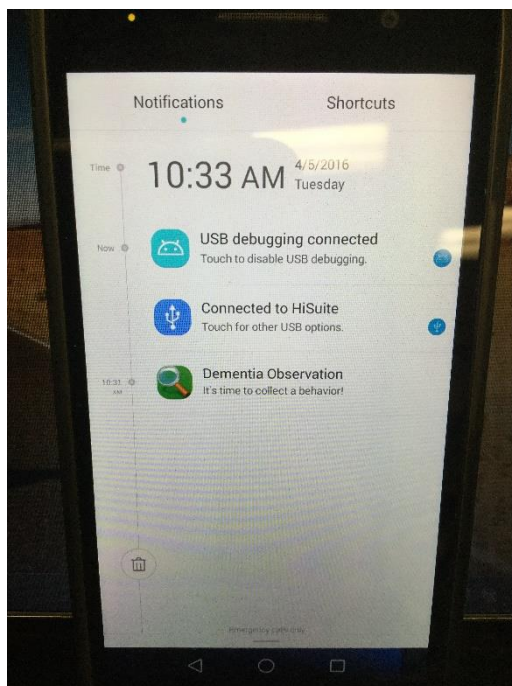
Export to excel

Export the patient’s behavioral records to computer over a couple of days. Using a wire to connect the device to computer and an Excel chart will be generated in the “Dobs” folder once clicking “EXPORT” button.



Setting function

Add some other functionalities like deleting current profile, enabling and disabling alarm and so on.



Alarm function

When the alarm is enabled through settings, the phone would issue a notification (ring and vibrate) every interval (15 minutes or 30 minutes).

Even when phone restarts, the alarm would still be able to remind caregivers to input a behavior without launching the application.

4. Lessons Learned

- **Specific Goals:** The framework of design should be planned thoroughly before actually starting coding. It would be great if details of the app are defined in early phase, such as the theme of the app, the appearance of screens, and the functionalities included. Once all the details are defined, the process of programming would be much specific. Programmers can just follow the development steps and avoid ambiguity. If the goals are not defined in the early phase, there would be lots of revisions in the process of programming. Sometimes, it may force programmers to start over, which is not desirable since it may affect the project schedule.
- **More Communication:** Communication is crucial for team members to work closely and productively. In the design phase, each member has different ideas of what the screens look like and how the app works. So more communication would allow us discuss which is better. In the development phase, problems may arise as to how to assign work. With more communication, work can be distributed more properly. Each member contributes to the completeness and perfection of the app.
- **Programming framework:** There are totally 45 classes designed, consisting of 11,501 lines of code in our app. So, from a programmer point of view, it is crucial to build a neat programming framework, achieve better coordination between classes, and implement object-oriented programming principles, such as data abstraction, class encapsulation, etc. It is easy to maintain and modify existing code as new objects can be created with small differences to existing ones.

5. Group Contribution

Cecelia Marshall(External Specialist):

- Identity: Social Worker at UHN – Toronto Rehab, Geriatric Psychiatry Services
- Formulated the idea of the app – a dementia observation behaviour tracking app, based on identified need in the field of dementia care towards improving mapping of behaviour patterns
- Developed initial mockup designs – app logo, face screen, behaviour and environment identifiers
- Outlined initial flow ideas
- Consulted with behaviour specialists and colleagues in development of ideas, and incorporated this into planning
- Throughout the spirals stages, trialled out progress with nursing and other potential end users, to incorporate their expertise
- Ongoing collaborative work with the programmers throughout the development – trialling new functionalities, providing feedback, identifying areas needing fixing from a user's perspective, and jointly developing presentations

Qiannan Zhao(Programmer):

- Implemented “MANAGE” function, including creating a profile, choosing monitoring behaviors, etc
- Implemented “Collecting behaviors” function (time, behavior and context)
- Implemented “Collecting incidents” function (time and incidents)
- Implemented ListView adapters to format database information to be readable
- Implemented “View behaviors” and “View incidents”
- Exported behavioral records between two dates to Excel charts

Dade Sheng(Programmer):

- Designed user interface (layout, icons, text formatting and etc.) based on initial mockup
- Implemented SQLite Database (structure as well as storage and retrieval functions)
- Implemented process of authentication of Fitbit wristband
- Fetched data(motion and sleep) from Fitbit server and transformed them to local readable objects
- Drew charts(motion and sleep) from transformed objects and created legends
- Implemented “ALARM” feature as well as issuing notifications

6. Specialist Context

Individuals with dementia are unable to express their thoughts, feelings, or needs effectively, so behaviours such as agitation and aggression often become their language for expressing distress. Understanding the meaning of behaviours, and their impact, has always been a challenge for caregivers. The DObs app has the potential to be a significant contribution to the area of behaviour observation and tracking in dementia care. At the time of its’ development, there were only two apps found pertaining to dementia with behaviours, but both were knowledge based with encyclopedia type functionality. The tools in the dementia field available to behavioural specialists have been paper based, unreliable, and with poor compliance. Furthermore, there was no method for analyzing collected data other than onerous transcribing of data.

Through initial demonstrations of DObs with nursing and other care staff, they have been impressed by the ease of the app for collecting observational data. Nursing and other caregiving staff are typically overloaded with direct care responsibilities, so it is difficult to get them to buy into a new work process. DObs simplistic functionality has been purposeful - to replace the current paper based DOS (dementia observation system) tool, DObs utilizes the same behaviour identifiers, which will ease the learning curve on the app. Front end caregivers, such as personal support workers, are typically less skilled and knowledgeable about behaviours. DObs requires a limited skill set to

operate for the collection of data. The setup and analysis of data will then continue to be done by the behaviour clinicians.

The addition of the environmental context is new to tracking, and a concept that has been overlooked in the field, but is essential for understanding behaviours patterns. Recognizing the influence of the environment as contributing or triggering behaviours is important for predicting and preventing behaviours. For example, if agitation can be seen as increasing when a patient is in noisy environments, then staff can be more aware to avoid such scenarios when possible.

The wearable device is a significant contribution towards tracking motor agitation/movement and sleep patterns. In analyzing the data, it enables staff to recognizing patterns of increasing agitation that are otherwise overlooked when caregivers are just capturing a behaviour in a single moment. This will be helpful in guiding treatment, such as influencing the timing of medications to avoid influxes in agitation, and to determine their effectiveness. Likewise, it was evident during the trialling of the wearable device, that disruptions in sleep patterns were not otherwise recognized. This will again enable clinicians to more effectively treat sleep disturbances, and ultimately reduce undesirable behaviour patterns such as irritability and aggression. Quality of sleep can also reflect underlying factors such as poorly managed anxiousness, depression, and unrecognized pain issues.

7. Future Work

The DObs app has the potential to be utilized in different environments, including specialized behaviour units, nursing homes, and private residential or family home settings. Plans are in development to trial the usability of the DObs prototype in the specialized behaviour unit at Toronto Rehab.

Further development would then be beneficial around the integrated analysis of data between the wearable and caregiver observation data, to further understand behaviour patterns. It would be ideal to have printable graphs for the wearable data, to clearly demonstrate motion and sleep changes rather than rely on review in isolation on the android phone.

Next steps would then be to explore for research opportunities to trial the app, and then towards potential marketing of the DObs assessment system. A poster presentation is scheduled for Technology and Dementia pre-conference day of the Alzheimer's Association International Conference in July 2016, to share around the development of DObs.