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# Activity Monitoring of People with Dementia in a Cognitive Stimulation Intervention †

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**Abstract:** Commercial activity trackers are increasingly being used to support healthcare research. While their accuracy has been questioned, they do provide more precise information on some parameters relevant to wellbeing than self-report, such as steps walked and sleep duration. Few studies, however, report on the use of these devices with people with dementia. We report the design and preliminary results of a cognitive stimulation therapy for people with dementia in which participants were monitored using activity trackers. We describe the strategies implemented to promote adoption and adherence of these devices, some of the issues we faced in the study and recommendations for future studies. An analysis of the results show that these devices are useful to show the differences in patterns of activity of the participants and were able to track differences in behavior in the days when the therapy intervention has held.

**Keywords:** activity monitoring; social robots; dementia care

## 1. Introduction

Smartwatches and fitness trackers are the most popular wearable devices, with activity tracking being one of its main uses. The sharp increase in sales makes it difficult to assess the prevalence of the devices but a recent estimate puts at 20% the number of users in Canada [1], while a survey conducted in 2015 among US adults estimated that 12.5% used fitness trackers [2].The proliferation of these devices has promoted their use in healthcare research [3], particularly in studies aimed at measuring physical activity, sleep and heart rate [4]. For instance, the analysis of more than 15,000 individuals using wearable devices found that these activity trackers provide useful information to identify individuals at risk of poor sleep [5]. Activity trackers have also been used to assess the effectiveness of an intervention aimed at physically activating breast cancer survivors who had completed chemotherapy and radiation treatment [6].

A search conducted in 2018 on MEDLINE found 81 studies that reported the use of activity trackers [7]. The most popular device used in these studies were Fitbits (54/81) with Garmin devices a distant second (22/81). The same study presents results of a search in the ClinicalTrials database which found a total 51 studies, 31 of which used Fitbits. Our own review of the 81 papers recovered in this study that only 2 of these studies focused on older adults [8,9] and a third includes a group of older adults in a comparison across age groups [10]. None of these studies focused on people with dementia. While no results have been yet reported, there is at least one clinical trial conducted in recent years involving people with mild cognitive impairment to assess the effectiveness of a sleep therapy [11].

There are several challenges associated with conducting healthcare research with people with dementia (PwD) using activity trackers and wearable devices in general. These include the acceptance

and adoption of the device and its withdrawal once the study is completed. Even removing the device for a short period to charge it might become an issue. The use of the device also imposes an additional burden to caregivers, who might be required to charge it or remove it during a bath or at night. When multiple caregivers are involved, as is the case with participants who are institutionalized, there's an additional coordination burden to account for the wearable device. An additional issue is that these devices have been designed for adults and in a few cases children, and do not take into account for instance, that frail older adults often walk in short steps and usually have lower heart rate variability. Activity trackers might be less accurate to assess some activities with this population. They are often used to collect personal relevant information for self-reflection and behavior change, thus acting as persuasive systems. The term Personal Informatics was coined to describe this phenomenon [12]. However, some of these features, such as goal tracking and alarms might be distracting and confusing to PwD and they might be a source of anxiety if some of these features cannot be deactivated. Finally, privacy and ethical concerns are raised from gathering data behavioral data from individuals not able to provide informed consent [13].

In the next section we describe a Cognitive Stimulation Therapy (CST) conducted in a period of nine weeks with ten PwD. The intervention consisted of one or two weekly therapy sessions with a conversational robot. Participants were equipped with an activity tracker for the duration of the intervention. The objective of this monitoring and the procedure followed are described in Section 3. In Section 4 we present the results of the monitoring study with an emphasis on the acceptance and adoption of the device and the behaviors recorded. Section 5 presents a discussion in the form of lessons and recommendations for researchers conducting similar studies.

## 2. A Cognitive Stimulation Therapy with a Conversational Robot

A Cognitive Stimulation Therapy (CST) consists of group sessions led by a facilitator. A CST aims to actively mentally stimulate participants through cognitive activities and reminiscence, multisensory stimulation and group social contact [14].

We developed a social and conversational robot called Eva to guide therapy sessions for people with dementia [15]. The robot Eva includes features such as natural language processing, emotion enactment and speech. Eva can work autonomously or through a human operator who can modify the robot's behavior using a web application. We designed a group therapy session using Eva's features. The therapeutic session includes elements of musicotherapy, reminiscence, cognitive games (complete to wisdom sayings) and relaxation. During the meeting, the robot Eva plays the role of the facilitator, guiding the sequence of activities, as well as turns for each participant.

### *2.1. Study Design*

For this study, we designed a CST composed by a set of therapeutic sessions which are conducted by the robot Eva. Based on the literature recommendations for a CST, the study was composed of 15 group sessions, two per week. A session was designed for three participants for approximately 30 min. However, the session duration depends on the number of participants.

The main objective of the study is to assess the behavior changes in PwD who participated in the CST conducted by the robot Eva. Based on a within-subjects design, we compare the behavior of the participants in days of sessions versus those in which no sessions were held.

### *2.2. Participants*

As the first step of the recruitment process, our research team conducted an introductory meeting with the primary caregivers and family members of the prospect participants. During the meeting, we explained to them aspects related to the study such as the use of social robots in CSTs, published impacts of a CST on PwD, description of the CST conducted by the robot Eva and privacy and ethical aspects related to the intervention. The following criteria were defined and explained to the family member. The inclusion criteria: (1) diagnosed with early and middle stage of dementia, (2) ability to

speak, (3) appropriate level of diction and (4) an adequate level of hearing. While the exclusion criteria were (1) frequent crisis of aggression and (2) delusion symptoms. Family members and caregivers who approved the participation of their relative should sign a consent letter. Approval for this study was granted by the Bioethics Commitment of CICESE (CBE/PRES-O/001).

We defined a three group session of three participants. Thus, a total of ten participants would be recruited, nine of them as primary participants and one who would participate in case another one could not participate on a given day.

### *2.3. Setup and Procedure*

The study was conducted in a lounge of the geriatric residence where all participants live. A facilitator welcomes the participants and introduces the robot Eva to them. The robot Eva conducts the therapeutic session and manages elements (music, conversation, relaxation) to focus on each participant (see Figure 1). Caregivers staff provides help to move the participants between sessions.


**Figure 1.** A therapeutic session with three participants conducted by the robot Eva.

### *2.4. Using Activity Trackers to Monitor Participants in the CST*

The main objective of this study is to compare the behavior of the participants in days where they assisted to the therapeutic session with the robot versus those without sessions. The most used methods to gather information related to the behavior of a PwD is an observer report, particularly those where the primary caregiver is an information proxy about activities, behavior and conduct of the patient. In general, these reports are completed offline; they could be reported days or weeks afterwards [16]. These reports depend on particular aspects from the informant such as memory, perception, context and attention. Thus, this kind of reports is not an effective way to capture accurate start and finish times for activities or location associated with activity information [17].

In order to gather useful information about the activities and behavior, we use activity trackers to monitor participants during the CST. We can gather quantitative information about the behavior of participants through the use of these devices. Although there are issues related to the accuracy provided by these activity trackers, we establish that these data can complement the information provided by the caregivers.

For this study, we used two bracelet models of Fitbit commercial devices: Charge 2 and Alta. Only the features related to activity level, steps and sleep monitor were relevant for this study. In addition, we gather heart-rate (HR) data from the Charge 2 model. We used the web-API (https://dev.fitbit.com/build/reference/web-api/) provided by Fitbit for accessing data from activity trackers and complete logs.

The use of a activity tracker is becoming prevalent in everyday life and, more recently, in healthcare research. However, we found very little on the use of these devices in studies conducted with PwD. Thus, in coordination with caregivers staff, we defined methodological strategies to deal with issues of the use of the activity trackers in PwD. These strategies focus on device aspects such as acceptance and adoption, loss prevention, charge and synchronization. Also, we used notes and interviews with caregivers to validate unusual data detected during the synchronization process.

#### 2.4.1. Acceptance and Adoption

The continuous use is a primary challenge in wearable devices for PwD. An initial and continuous strategy to promote the use of the activity trackers is necessary. Many older adults have known and worn devices with a similar appearance such as a hand watch. Using this similarity, we present the devices to the participants as a classic hand watch. In addition, we explain to them the additional features (activity, sleep, HR) as a way to know more about their health. This strategy should be frequently used because there are daily activities which require them to take-off and wear the device again (e.g., taking a shower, charging battery) or when caregivers staff detects that a participant has taken-off the device without any reason.

#### 2.4.2. Loss Prevention

A common conduct in PwD is to leave behind and loose personal articles. Thus, it is highly probable that they might misplace or loose the activity tracker. The caregivers' supervisor defined a plan to monitor the use and localization of the devices. Thus, each caregiver made a report at the end of their working day. Reports include who is wearing the device; if someone refuses to use the device, where is the device; and additional notes about issues during the day. The next turn of caregivers uses the report to avoid and deal with possible contingencies.

#### 2.4.3. Charge and Uploading

Technical specifications for models used (Fitbit Charge 2 and Alta) in the study indicate that the battery lasts around six or seven days. In such a way, we planed weekly meetings to charge the battery and upload data from the devices. A member of the research team visited the residence at least once a week to charge all activity trackers for four hours, to guarantee a full charge. At the same time, the team member synchronized the data from the internal memory to the cloud server using a smartphone. During this process, it is necessary to explain to the participants how important it is to charge the battery for the device to work properly.

#### 2.4.4. Validation of Unusual Data

We conducted a quick analysis of the data gathered per week. The objective of this analysis is to detect unusual activity in participants based on their historical data (e.g., null activity, an excessive number of steps, strange sleep activity). If unusual data is detected, we interview the caregivers (as soon as possible) to validate or discard this data from the dataset. Besides, we kept a log of comments made by the caregivers for the same purpose.

## 3. Results

A total of ten older adults (6 female and 4 male), aged between 72 and 95 (Mean = 82.6, SD = 8.52), participated in the study (see Table 1). Their MMSE scores denote mild to moderate-stage dementia (Mean = 14.57, SD = 3.57). Originally we recruited 9 participants but one of them left the residence and the study after six sessions and we decided to incorporate a new participant (P10) from session 8.

**Table 1.** Participants in the study.

| Id | Gender | Age | MMSE | Sessions Attended | Days Using the Device |
|---|---|---|---|---|---|
| P1 | M | 74 | 17 | 14 | 71 |
| P2 | F | 76 | 18 | 10 | 39 |
| P3 | F | 86 | 10 | 6 | 22 |
| P4 | F | 95 | 15 | 14 | 70 |
| P5 | F | 71 | 9 | 14 | 66 |
| P6 | M | 90 | 17 | 13 | 63 |
| P7 | M | 88 | 19 | 10 | 71 |
| P8 | F | 86 | 14 | 14 | 62 |
| P9 | F | 86 | 12 | 9 | 66 |
| P10 | M | 72 | - | 7 | 14 |
| AVG | 4M/6F | 82.4 | 14.57 | 11.1 | 54.4 |

Eight caregivers actively participated in the study, including a supervisor who set some of the guidelines for the handling of the wearable. Except for the supervisor, caregivers were divided in two main areas of the residence. Two of the caregivers left the residence in the middle of the study and an additional one substituted one of the vacancies and got involved in the study and informed of the procedures in place regarding the wearables.

### *3.1. Adoption and Adherence*

Five of the participants wore a Fitbit Charge 2 HR, while the other five used a Fitbit Alta. On average they wore the activity tracker for 54 days. Figure 2 shows the number of days that participants used the device. P3 used the device only for 22 days since she left the residence and the study. When she left the study we incorporated P10 for which we have a total of 14 days of data. We initially gave the activity trackers to some of the participants to familiarize caregivers and participants with the device and the procedures we implemented for charging them and the handover with each change of shift. Due to difficulties configuring one of the devices P8 and P9 received the device after the second therapy session.

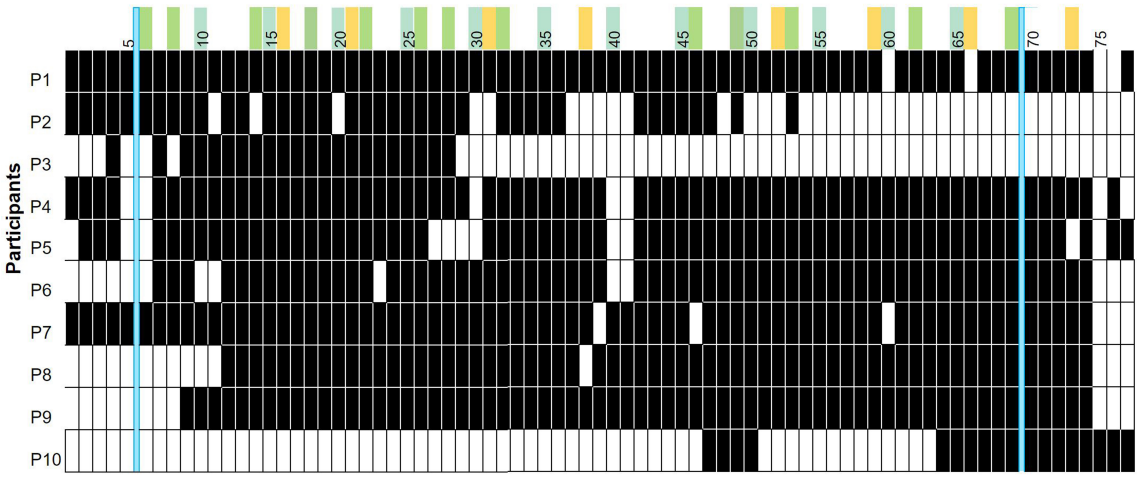


**Figure 2.** Utilization of activity trackers by participants per day - black = wore it, white = not wore it. The blue lines indicate first and last day of the CST. The green columns indicate days when a therapy session was held. Yellow marks are days when devices were charged.

While one of the main advantages of using wearables in health studies is their capacity to record data 24/7, adoption and adherence are issues frequently faced in the use of these devices. Older adults in particular might find it uncomfortable to wear the device at night or they might just forget to put it on [18].

In our study, we found significant differences in adoption between participants. On the one hand, most participants quickly adopted the wearable, several of them interested in using it as a watch. We told participants that the device could be used as a watch but it also allowed them to measure their steps and how much they slept. Two of the participants often refused to take off the device when it required charging and it took some convincing to make them give it up. In one instance we had to wait until the battery ran off to convince P1 to give us the device to charge it. In another case the caregiver gave P6 his own watch for several minutes while we charged the activity tracker. We left both of these participants the device for a few days after the study ended, until they agreed to give it up.

On the other hand P2 showed some reluctance to wear the activity tracker from the beginning. Initially she was particularly interested in knowing how much she walked, she asked how much she should walk each day and learned how to consult this information in the device. However, she would take the device off at night and left it on her night stand. She expressed concern that she would damage the activity tracker or lose it. We tried different strategies such as telling her that the device was hers to keep and there was no problem if it got damaged. We also reminded her of the step-counting feature but she replied that she already knew how much she walked. Thus, we decided to withdraw the activity tracker but she continued to participate in the therapy sessions.

P5 wore the activity tracker most of the time but took it off occasionally and left it around the residence. In a couple of instances caregivers and researchers had to look for the device in the residence for a few hours before they found it. She was not very conscious of the device. In a few occasions when we asked her for the device to charge it, she would tell us that she did not have it. Then we asked her to show us her wrist and she was surprised to see that she was actually wearing the device. She wore a Fitbit Alta with the original band which is relatively easy to remove. We believe that a different band would have helped her achieve higher adherence.

In summary we had 6 participants with very good adoption, wearing the activity tracker most of the time. Two participants who were reluctant or took off the device themselves with some frequency and two additional participants with good adoption but who only participated in about half the length of the study and used the device for a short period of time.

As shown in Figure 2 some of the user did not use the activity tracker on some occasions. A caregiver for instance told us that she took the device off before bathing a participants and forgot to put it on again, leaving it in the caregiver's pocket for the rest of the afternoon.

A similar event occurred with P6, who left her activity tracker in the pocket of his pants, which were then sent to the washing machine. We could clearly identify this episode from the spike in activity recorded by the device and we could eliminate this data from our analysis. However, while both the caregivers and the researchers were frequently making sure that the participants were wearing the activity tracker and registering periods when they took it off, it was not possible to detect all of those instances.

Besides the logs from the researcher and caregivers on usage we correlated data from heart rate and activity to identify periods when the activity tracker was not being worn.

The protocol we implemented to charge the activity trackers and download the data worked fine. However, the device did not record sleep data in some nights. In most of these cases the activity and heart rate data seemed consistent with sleep activity (zero steps and HR measures consistent with rest values) but for some reason no amount of sleep was recorded. Other Fitbit users have reported similar problems.

### 3.2. *Activity*

Table 2 shows the average number of steps taken by each of the nine original participants for the four hours following their participation in each therapy session (T), as well as for the same period of time on days in which there was no therapy (NT). We took the period between 1:30 to 5:30 pm to assess the potential effect of the therapy to physically stimulate the participants. The table shows that six of the participants had more physical activity after the therapy sessions, while the other three

experience a reduction in number of steps. There's a notable difference in the amount of physical activity among participants, with P1 taking an order of magnitude more steps than most of the others and six participants walking an average of less than 10 steps per hour. While some of the participants are frail and have reduced mobility, this low number can partially be explained by an underestimation of the number of steps by the activity tracker which is not calibrated for frail users. Low-intensity activity could have been a better estimate of physical activation, unfortunately the devices we used only records the number of minutes of null, low, moderate and intense activity per day, without indicating how active they were at a particular time of the day. Access to raw accelerometer data could be used for a more detailed analysis. Except for P1, who registered some moderate activity, all other participants had no moderate or intense activity recorded.

**Table 2.** Average number of steps between 1:30 and 5:30 pm on days when therapy sessions were held and days with no therapy.

| Participant | Therapy | SD | No Therapy | SD |
|---|---|---|---|---|
| **P1** | 853.47 | 687.08 | 680.78 | 644.85 |
| **P2** | 72.2 | 60.45 | 63.73 | 82.62 |
| **P3** | 17.6 | 33.05 | 28.18 | 28.92 |
| **P4** | 22.38 | 31.99 | 15.26 | 33.73 |
| **P5** | 112.75 | 107.55 | 102.67 | 160.13 |
| **P6** | 7.14 | 10.06 | 17.59 | 35.15 |
| **P7** | 19.64 | 37.40 | 18.09 | 37.56 |
| **P8** | 14.33 | 15.95 | 36 | .23 58.43 |
| **P9** | 27.71 | 51.92 | 21.78 | 44.72 |

Figure 3 shows the average amount of activity throughout the day (as measured by number of steps) of the three more active participants. Each square represents 30 min and the darker the color the higher the number of steps registered by the activity tracker in that period. Again, P1 is clearly the most active of them. He often experiences anxiety and wanders around the residence. On the other hand, P5 has been medicated for the last few months to control her anxiety. This calms her down in the mornings but as the effect of the medication wears down, she becomes more active in the afternoon.

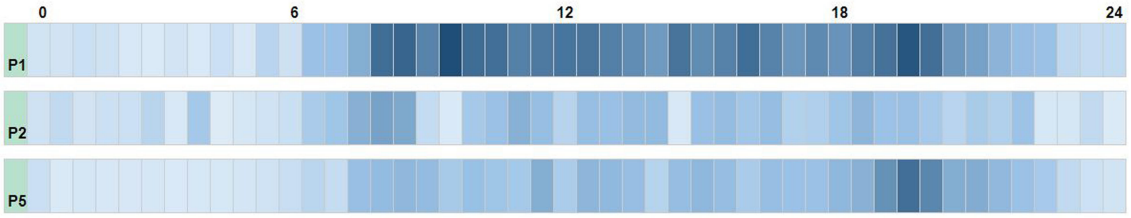


**Figure 3.** Average number of steps of the three more active participants during the day.

### *3.3. Sleep*

It has been estimated that between 60 and 70% of people with dementia or cognitive decline experience sleep disturbance. These include sleep fragmentation, abnormal sleep duration and frequent daytime sleep [19]. Poor sleep is one of the main complaints of caregivers [20], increasing their burden on informal caregivers [21] and leading to a decision to institutionalize older adults.

Table 3 shows some of the sleep parameters recorded for the 5 participants who participated in at least 10 sessions wearing the device. It shows that 4 of them slept more on the nights when 3 of them had sessions with the robots and had less daytime sleep in the afternoons when the therapy sessions were held. For instance, P1 had on average 519 min of nighttime sleep and 91 min of daytime sleep on the 42 days recorded in which there were no sessions with the robot. Nighttime sleep increased to 566 min and daytime sleep decrease to 65 min for days with sessions. Both results are statistically significant ($p < 0.05$). Daytime sleep was recorded as periods when the participant slept in the

afternoon, outside their normal sleep periods. We consider only daytime sleep in the afternoon in order to compare days with sessions with the robot and those without session, since the sessions took place between 11am and 1pm. During the post-intervention interviews, one of the caregivers told us that she noticed that P6 and P8 slept less during the afternoon on days where the therapy tool place, corroborating the results obtained from their activity trackers.

**Table 3.** Nightime and daytime sleep for the 5 participants who participated in at least 10 therapy sessions.

| Participant | Night/Therapy (n) | Night/NO Therapy (n) | Day/Therapy (n) | Day/NO Therapy (n) |
|---|---|---|---|---|
| **P1** | 566 (12) | 519 (42) | 65 (4) | 91 (11) |
| **P4** | 403 (13) | 283 (41) | 102 (1) | 92 (4) |
| **P6** | 536 (9) | 543 (41) | 0 (0) | 83(8) |
| **P7** | 488 (11) | 394 (47) | 0 (0) | 0 (0) |
| **P8** | 519 (11) | 482 (36) | 62 (1) | 119 (9) |

P7 has some peculiar sleep patterns. He has reduced mobility and is often seated during the day and frequently takes brief naps that the wearable does not register as sleep periods. At night he experiences fragmented sleep, often sleeping for a couple of hours to then wakes up for 1 to 3 h before getting back to sleep for a few additional hours. However, on the 11 days when he participated in therapy sessions we only detected 3 such sleep disruptions (27%), while he experienced disrupted sleep on 18 of 46 nights when there was no therapy (39%). This seems to indicate that the cognitive stimulation of the sessions had a positive effect on the quality of his sleep. Indeed caregivers told us that they observed that P7 slept better on days when he participated in therapy sessions.

### *3.4. Heart Rate*

Figure 4 shows the average heart rate of participant P8 during one of the sessions with the robot. The resting heart rate for this participant is 62 bpm. The figure clearly shows an increase in heart rate when the participant is singing and a similar drop in HR during the relaxation segment of the session.

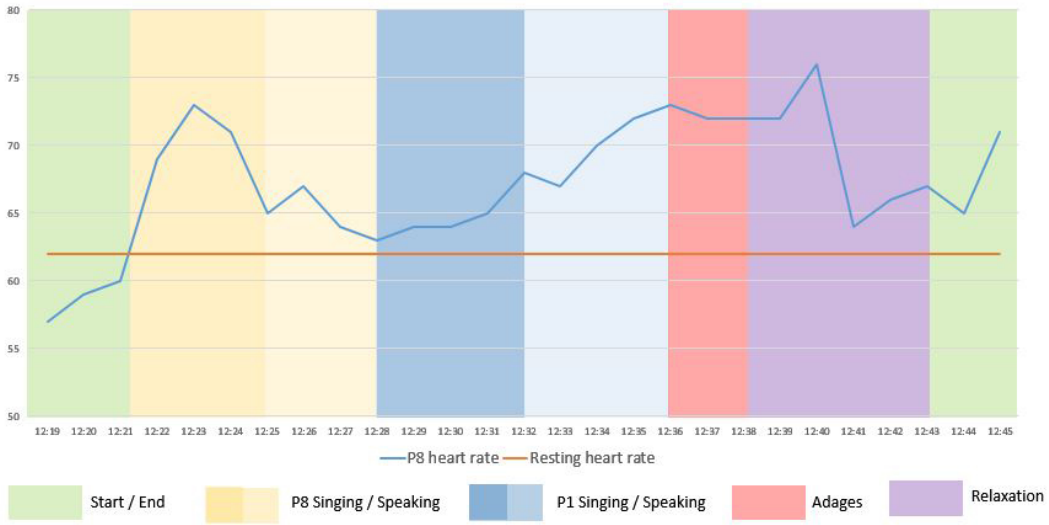


**Figure 4.** Average heart rate of P8 during sessions S9.

Heart rate data also proved useful to identify periods in which the activity trackers were being used by the five participants who used the fitbit Charge 2HR.

## 4. Discussion

We summarize our main findings in the form of recommendations to researchers considering the use of activity trackers in pervasive healthcare studies with older adults with dementia living in a residence.

Caregiver involvement was key in achieving high adherence and in understanding participants' behavior regarding the use of the activity trackers. This oversight by caregivers is an important distinction with respect to most studies in which usage follow up relies mostly on the participant. The use of the devices puts some additional burden on caregivers and this should be clarified to them from the beginning of the study. We thus recommend to get caregivers involved early in the study and re-distribute their workload if necessary.

Two of the original participants stopped using the activity tracker during the study. One of them left the residence and the second one decided not to continue wearing the device two-thirds into the study. Attrition rates, or patient dropout, are normally taken into consideration in studies with older adults and particularly those with dementia [22]. If tracking devices are to be used, these rates should be increased to account for those not willing to use the device at some point in the study.

Most participants expressed an interest in some of the functionality of the activity tracker, most notably the watch and, to a lesser extent, the step counting. However, some of the features proved distracting to them. P10 for instance mentioned that the wearable would turn on at night when he moved. P1 would often tap on the activity tracker to look at the different information displayed, such as time, number of steps and so forth. His interest in the information proved useful at times, as one of the caregivers told us that when P1 became anxious, the caregiver distracted him by talking about the device. In any case it would be useful to be able to control the information that can be displayed (for instance deactivate notifications) as well as its format, as is the case with smartwatches. This could be customized for each user with a default option of only showing time.

Most activity trackers today are worn on the wrist. This format proved satisfactory for our study. It allowed us to register heart rate from the five participants who used the Fitbit Charge 2 and get more accurate measures of sleep periods. However, for some participants other form factor might be more appropriate, such as being able to wear it more discreetly in the belt, on the shoe or in the cloth. Of course, some of these form factors have other disadvantages, such as making it more difficult to record sleep. Additionally, we gave all participants the device with the wrist-band that ships with the activity tracker. However, other bands would have been more appropriate, such as elastic bands and smaller ones for some of the participants that have thin wrists. Being able to have bands of different colors would have also helped us differentiate which wearable belonged to whom. One of the caregivers told us that once they mistakenly switched activity trackers among two participants, switching them back to the original owner a couple of hours later when they realized this. This led us to color code each activity tracker to facilitate caregivers handle of the devices. Using bands of different color or material could also help some participants clearly identify their own device.

Bathing was one of the activities that lead to caregivers taking the activity tracker off for a short period of time and lead to problems such as misplacing them for some time or arguing with some of the participants who resisted taking it off. The newer generation of activity trackers, to a large extent are waterproof and can be used in the shower or while swimming. The use of these devices could have eased some of the burden on caregivers and reduce periods when participants did not wear the device.

We decided not to place additional burden on caregivers by asking them to charge the activity tracker. However, it would have been useful to have them charge the devices for shorter periods of time more frequently, for instance when bathing them.

Finally, some of these commercial activity trackers only provide summative data. Notably, level of activity is only reported as minutes per day. Having access to raw accelerometer and gyroscope data could allow us to do our own processing for activity and behavior recognition. In particular it would have allowed us to better track mobility, since for frail adults with mobility restrictions steps are not counted accurately.

## 5. Conclusions

We have studied the adoption and usage of activity trackers by ten older adults with dementia for a period of ten weeks. The devices were provided to the study participants to assess the effects in their behaviors of a cognitive stimulation therapy conducted by a conversational robot. The activity trackers were well received and most participants adopted the device, one of the participants took the device off frequently and another one decided to stop wearing after about two thirds of the study had been completed.

While the activity trackers have some accuracy limitations and we could not always know when the device was being worn, we were able to identify changes in behaviors that were confirmed by the caregivers.

The lessons learned that can be useful in similar studies include getting caregivers involved early in the process, consider the fact that some participants might reject to use the activity tracker or stop using it after some time and customizing the device to the individual to make it comfortable and not distracting.

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**Conflicts of Interest:** The authors declare no conflict of interest.

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