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Naturalistic enactment to elicit and recognize caregiver state anxiety

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Abstract Caring for people with dementia imposes significant stress on family members and caregivers. Often, these informal caregivers have no coping strategy to deal with these behaviors. Anxiety and stress episodes are often triggered by problematic behaviors exhibited by the person who suffers from dementia. Detecting these behaviors could help them in dealing with them and reduce caregiver burden. However, work on anxiety detection using physiological signals has mostly been done under controlled conditions. In this paper we describe an experiment aimed at inducing anxiety among caregivers of people with dementia under naturalistic conditions. We report an experiment, using the naturalistic enactment technique, in which 10 subjects were asked to care for an older adult who acts as if she experiences dementia. We record physiological signals from the participants (GSR, HR, EEG) during the sessions that lasted for approximately 30 minutes. We explain how we obtained ground truth from self-report and observation data. We conducted two different tests using the Support Vector Machine technique. We obtained an average precision of 77.8% of and 38.1% recall when classifying two different possible states: "Anxious" and "Not anxious". Analysis of the data provides evidence that the experiment elicits state anxiety and that it can be detected using wearable sensors. Furthermore, if episodes of problematic behaviors can also be detected, the recognition of anxiety in the caregiver can be improved, leading to the enactment of appropriate interventions to help caregivers cope with anxiety episodes.

Keywords: Anxiety estimation; Naturalistic Enactment; Dementia; Wearable sensing; Anxiety elicitation; Physiological signals.

1. INTRODUCTION

It has been estimated that between 5 to 7% of those 60 and older suffer from dementia, with the total number of persons with dementia (PwD) expected to double every 20 years worldwide [1]. Dementia is characterized by changes in personality and behavioral functions that can be very challenging for caregivers. Informal caregivers, mostly family members and friends, can be affected from the loss of intellectual functions and the inability of the PwD to perform activities of daily living. PwD presents behavioral and psychological symptoms of dementia (BPSD) that impose additional burden on caregivers. These symptoms, which are estimated to be present in 90% of PwDs [2], include aggression, agitation, wandering, verbal aggression or psychosis, and affect caregivers and eventually undermine their health and capacity to care for the PwD.

A recent study estimated that 60% of caregivers develop anxiety or depressive disorders in the first 24 months of caring for a person with dementia [3]. Almost 25% of them have a significant clinically anxiety level [4]. Moreover, dementia care is particularly stressful, demanding more hours and complications on informal caregivers, than the care of non-dementia patients [5]. Another study reported that caregivers suffering anxiety experience a death rate 63% greater than non-caregivers of the same age [6].

Numerous strategies have been proposed to deal with caregiver anxiety. These can be classified as: Focused on emotions; Based on problem resolution; and dysfunctional strategies [4]. Caregiver burden increases when dysfunctional strategies are used more frequently while problem solving strategies decrease [7]. Monitoring coping strategies can help predict caregiver anxiety and burden [8].

Recent work has been done on stress and anxiety recognition within pervasive healthcare [9-11], however none of them have focused on caregivers. Clinical approaches to detect stress among caregivers are based on self-report [12-14]. In contrast, our interest is on detecting anxiety without the intervention of the subject.

This work focuses on State Anxiety, which is experienced when the subject is confronted with a specific situation [15]. While caregivers can experience continuous stress that could lead to long-term anxiety, detecting and dealing with anxiety episodes triggered by specific events, such as problematic behaviors by the person with dementia (for instance verbal abuse), can help in instrumenting adequate coping strategies aimed at improving the caregiver-PwD relation.

2. AMBIENT-ASSISTED INTERVENTIONS FOR CAREGIVERS

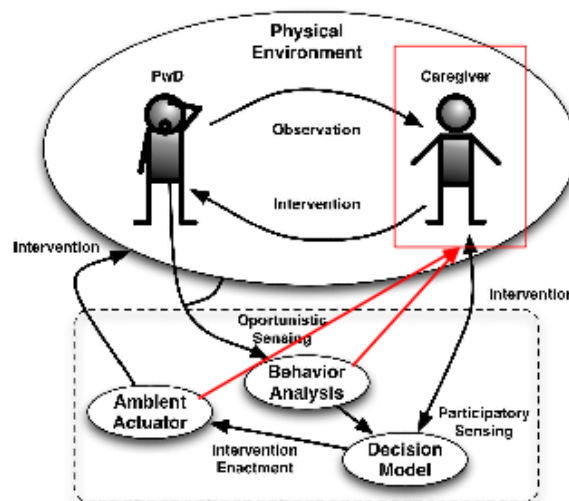
An Ambient-assisted Intervention System (AaIS) focuses on proposing, or directly enacting, strategies aimed at

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4 addressing problematic behaviors exhibited by a PwD [16]. An AaS uses ambient intelligence to improve PwDs quality of
5 life by identifying the presence of BPSDs, deciding on an appropriate intervention, and either modifying the environment
6 or persuading either the PwD, or the caregiver, to act on the system's advice. Both, inappropriate environments and
7 upsetting personal interactions combine with unmet needs to trigger problematic behaviors. For instance, a PwD might
8 exhibit apathy after being scolded by her caregiver or might undergo wandering triggered initially by her need to move
9 after a long period of rest [17]. When detecting these behaviors the AaS could, for instance, recommend the caregiver to
10 encourage the PwD to help with simple house chores or take a walk around the block with him. With feedback from the
11 caregiver as to the efficacy of the strategies proposed, the AaS can be trained to offer effective recommendations.

12 By detecting problematic behaviors and inferring probable causes, behavior-aware applications can provide tailored and
13 opportune interventions, such as notifying caregivers, offering assurance to the patient, or directly modifying the physical
14 environment. For example, as daylight decreases at nightfall, a person with dementia might experience confusion and
15 anxiety for not being able to recognize his or her surroundings. This could lead to a desire to wander, a phenomena
16 known as sun downing syndrome. An approach to deal with this behavior is to increase the lighting conditions.

17 We propose to extend the AaS framework to analyze the behavior of caregivers and enact coping strategies that would
18 assist them in dealing with situations that cause them stress or anxiety. Thus, rather than enacting strategies to deal with
19 problematic behaviors, in this case the strategies are aimed at reducing the negative effects of these behaviors on the
20 caregiver by enacting or suggesting adequate coping strategies, as illustrated in Figure 1.

21 An important aspect of the extended AaS framework is the detection of negative behaviors in the caregiver, such as
22 anxiety or stress. These behaviors might also trigger problematic behaviors in the PwD, since emotional contagion has
23 been found to grow stronger in PwDs. That is, the PwD might sense anxiety on the caregiver, and unconsciously mimic
24 that behavior [18].



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45 **Figure 1.** Extended AaS framework that includes assisting the caregiver in dealing with stress and anxiety.

46 In this paper we describe an experiment aimed at eliciting anxiety on informal caregivers and collecting physiological data
47 from them under stressful conditions from which this negative behavior can be inferred. The next section describes the
48 experiment conducted.

49 50 51 **3. AN EXPERIMENT TO ELICIT ANXIETY ON INFORMAL CAREGIVERS**

52 We designed an intervention to induce anxiety on informal caregivers under controlled and naturalistic conditions. To
53 achieve this we applied a technique known as Naturalistic Enactment (NE) [19]. NE was originally proposed to evaluate
54 pervasive healthcare technologies, where having high ecological validity and direct user involvement is important, yet
55 using actual patients can put them at risk. NE consists of a naturalistic enactment of tasks (i.e. the exposure to situations
56 and tasks in natural conditions) to simulate the experience of the user under normal conditions, and thus unearth issues
57 and behaviors that would otherwise have been difficult to capture.

58 Naturalistic Enactment represents an alternative to either the use of a controlled experiment in which a single stimuli,
59 known to generate the expected emotion, is provided to the subject, or to follow the subject in their everyday activity with
60 the hope of recording instances of the behavior of interest. An example of the former is the Trier Social Stress Test, in
61 which individuals are asked to make a 5-minute presentation, for instance a job interview, in front of a group of people
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4 wearing white coats [20]. There is ample evidence that this situation generates anxiety in most participants, however, the
5 stimuli is very different from the one experienced when caring for a PwD. On the other, several techniques have been
6 proposed for data collection from people performing their every day activities. Using Participant Observation, a researcher
7 observes the subject and records behaviors and conditions. A limitation of this method, particularly for observing
8 behaviors such as anxiety, is that the researcher might influence the participant's mood or his desire to disclose his mood.
9 An alternative approach for naturalistic data collection is the Experience Sampling Method [21], in which subjects are
10 asked to record their feelings and experiences in real-time, this can be done either periodically or opportunistically.
11 However, this technique is not precise enough to synchronize the physiological data being gathered with the anxiety
12 experienced by the subject. This would require the individual to recognize that he is experiencing anxiety and at that
13 moment record the experience, which in itself might change his mood.

14 By using Naturalistic Enactment we put the subject in a condition that is controlled to elicit anxiety, and thus can be
15 reproduced with other subjects, and yet it is perceived by the individual as a typical caregiving situation, which will make
16 him act and react naturally.

17 In order to expose our subjects to a realistic and stressful caregiving situation under controlled conditions, we conceived
18 an exercise that consisted of a naturalistic enactment of a therapy session with a person acting as being a PwD. An elder
19 of 75 years old acted as if she suffered from mild dementia. She was trained with typical behaviors such as: mumbling,
20 screaming, wandering, repetitive questioning, among others. She was already familiar with these behaviors from
21 acquaintances that suffer from dementia. The participants were told that they would be working with a person who actually
22 suffers from dementia.

23 Written consent was obtained from all participants before the first session and a non disclosure agreement was also
24 signed to avoid the participants to talk to each other about the experiment, the behaviors of the elder or any techniques on
25 how to handle the elder's behavior, for as long as the experiment lasted.

26 **3.1 SUBJECTS**

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28 The subjects were recruited by sending an email to the University's graduate students. A compensation of two movie
29 theater tickets was offered, although many of them expressed interest in participating in spite of the prize. Participants
30 consisted of 10 graduate students (5 male, 5 female) with an average age of 24.7 (St. dev. = 1.0593).

31 **3.3 THERAPY TASKS**

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33 For five minutes, and once instrumented, the subjects relaxed by concentrating on their own breathing with eyes closed to
34 obtain baseline physiological data. Participants were asked to guide the older adult through a therapy session, which
35 involved two of the 8 tasks that were explained during the training session. These included activities such as Lace tying,
36 image classification and object separation

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38 The whole intervention was conducted over 3 weeks, during weekdays, for a total of 15 days. Each participant conducted
39 a therapy with the older adult lasting approximately 30 minutes. Each day two participants assisted to the site.

40 **3.4 SETUP**

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42 We settled a room to make it look as if a person with dementia lived there. This included: old furniture, low illumination, old
43 pictures and paper hint tags over the hand washer. A laptop, a video camera, and a smartphone were used to monitor the
44 experiment.

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46 Two researchers stood at the wooden table to operate the equipment and take notes. We sat both the participant and the
47 elder face to face in a circular table.

48 **3.5 DATA GATHERING**

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50 Before beginning the task, we provided participants with an electrical pulse reader (Zephyr Hxm) on the chest to monitor
51 heart rate/Inter-beat Interval, an Empatica E3 wristband to get Galvanic Skin Response data and a Muse band EEG
52 monitor. All sessions were videotaped for further analysis.

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54 For the first device, we developed the "Care Me Too" application for Android, which connects via Bluetooth Low Energy.
55 Figure 2 shows the "Care Me Too" application running on an Android device.
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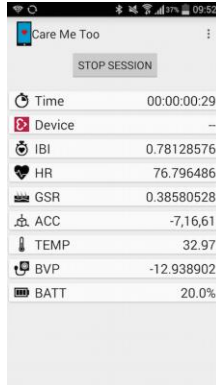


Figure 2. The “Care Me Too” Android application displaying values from different sensors.

For the Zephyr HxM program, we used the `anxiLogger` command line program (<https://github.com/panzerfausten/anxiLogger>) developed for an earlier study [22].

4. ESTABLISHING GROUND TRUTH

Establishing ground truth was a challenging and time-consuming task. Each session took us around 10 hours of work to complete. All videos from the sessions were analyzed to segment the events of interest, namely, when the older adult enacted a behavior that could induce anxiety on the subject. For instance, in one case the older adult, while engaged in the therapy asks the subject: “*Where is my mother?*” These segments were classified as one of four possible levels according to the criteria described in Table 1. Behaviors in level 0 are not likely to elicit anxiety, while those in level 3 are very likely to surprise the participant and produce state anxiety, as the subject experiences a loss of control over the situation.

Table 1. Event codification criteria.

Level	Criteria	Event example
0	PwD is passive, PwD is willing to participate, Participant and PwD are engaged with the task.	The PwD performs the activity as requested
1	Reluctant behaviors, Unwilling to participate, Complaining about the task.	“I don t like this game”, “This is too hard” , “Do it yourself”
2	Mumbling, Talking nonsense, Unpredictable behavior.	“Where is my mother?”, “Who are you?”
3	Shouting, Threatening the participant, Paranoia, Urge to leave.	“MOTHER, WHERE ARE YOU!??” , “I WANT TO LEAVE NOW!”, “WHO ARE YOU? LET ME GO!”

In order to obtain ground truth, two researchers coded the sessions live, by taking notes of time, level of perceived anxiety, and a description of the event. This description was noted by either what the participant and/or the elder said or did at the moment. The participants were asked to record in a paper form their anxiety level whenever they felt it changed. Figure 3 shows the format filled by one of the participants.

Formato de autoreporte del cuidador

Nombre: Alfonso Velasco		Actividad: Organización de objetos		Hora de inicio		
Ensayo	Pido	Respuesta	Ayuda	Comentarios	Nivel de ansiedad	Hora de fin
1		SI	NO	Primeros tabs bien	1 3 4 5	4:15
2		SI	NO		2 3 4 5	4:18
3		SI	NO	Una y una	1 2 3 4 5	4:19
4		SI	NO		1 3 4 5	4:20
5		SI	NO	Se despara	1 2 3 4 5	4:21
6		SI	NO	No te gusta, pero lo hace	1 2 3 4 5	4:23
7		SI	NO	Se caen los fichas	1 2 3 4 5	4:24
8		SI	NO	Pregunta por si mismas	1 2 3 4 5	4:26
9		SI	NO	No se quiso decir	1 2 3 4 5	4:26
10		SI	NO	Cambio de juego	1 2 3 4 5	4:28
11		SI	NO	Narras: lo hizo bien	1 2 3 4 5	4:30
12		SI	NO	Aumentar tabs	1 2 3 4 5	4:32
13		SI	NO	Acepto de 4	1 2 3 4 5	4:33
14		SI	NO	Lo hace bien	1 2 3 4 5	4:34
15		SI	NO	Bueno mate, corre, corre mate	1 3 4 5	4:37
16		SI	NO	Las últimas fichitas mal y	1 2 3 4 5	4:40
17		SI	NO	correctas bien.	1 2 3 4 5	
18		SI	NO		1 2 3 4 5	
19		SI	NO		1 2 3 4 5	
20		SI	NO		1 2 3 4 5	

Figure 3. Format used by the participants to report their anxiety level.

Finally, we partitioned each session in 30 seconds segments and labeled them as “No anxiety” and “Anxiety”. A third label “ambiguous” was used when the data was not enough to discriminate the presence of anxiety. To determinate the label we used the observation data, auto-report and the analysis recorded video. For the video we used a heuristic of the subject movements, voice tone and eye gaze.

5. DATA PROCESSING

EEG has been correlated with affective states [23], thus we estimated the correlation between eye blinking, obtained from the EEG signal, and the state of anxiety as estimated from the approach described above. Correlation varied from 0.78 to 0.91, which is relatively high, but insufficient to be used as a substitute for ground truth. Besides, there are episodes where the EEG signal is poor because the subjects move during the session, producing noise. However, it is worth pursuing this approach since it could help reduce the labor-consuming task of video segmentation and annotation.

We developed a python library to process all the physiological data, including export, feature extraction, timestamp synchronization, and plotting anxiety data from all the devices. We started by down-sampling the GSR data from 4.0 Hz to 1.0Hz. Then we detected signal peaks and filtered those greater than a threshold ($t \geq 0.04$ for not normalized data). We also calculated the “Half Recovery Time” of the signal.

Since the heart rate sensor only reports data when the heartbeat happens. We only grouped the data in windows of one second to compare it with the rest of the signals.

6. RESULTS

The physiological data collected was used to create models to infer anxiety using the Support Vector Machine algorithm. We present the results from 5 individuals, those with more self-report data, from which we had more reliable ground truth. As ground truth we used the “anxiety” and “not anxiety” segments obtained as described in section 4.2. All the segments were 30 seconds long. In all the tests we used 9 features the GSR and IBI signals. For GSR we used Peaks amplitude, Maximum peak amplitude, Minimum peak amplitude, Peak variance, and Average half-time recovery. The features used for IBI are: Minimum, Maximum, Average and Standard Deviation. A total of 212 “anxiety” segments and 310 “not anxiety” were obtained.

Figure 4 shows the anxiety spans obtained for session number 1 of participant 7. The IBI signal is displayed on top. Red segments correspond to anxiety spans, green to not anxious spans and gray ones were classified as ambiguous.

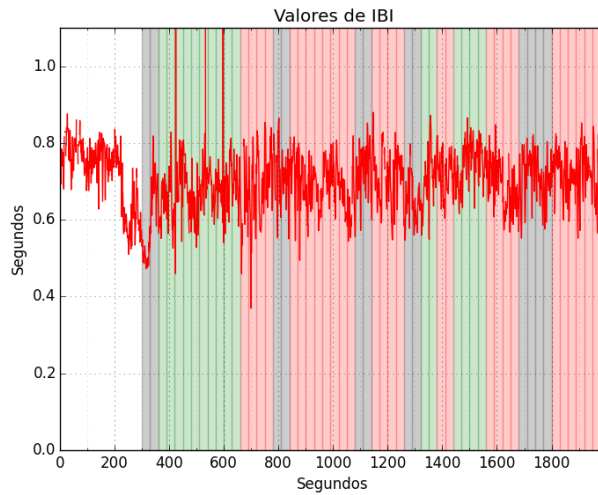


Figure 4. Classification results for Participant 7, session 1 with the IBI signal shown on top.

We conducted a “Leave-one-out” cross-validation test. For each participant, we took the data from the rest of the participants to train the model and the participant data to test it. A SVM model with a radial basis function kernel was used. We also conducted a separate test for GSR, IBI and GSR + IBI signals. Table 2 shows the results obtained.

Table 2. Classification results per signal

Signal	Precision (RBF)	Recall (RBF)
GSR+IBI	76.21	36.14
GSR	76.78	31.49
IBI	80.37	46.75
AVERAGE	77.79	38.12

The average precision was 77.79%, with the best results obtained using only the IBI (80.37). This is in part explained by the different patterns in GSR observed in the sessions. Indeed, IBI has been reported to correlate well with stress [24]. Recall, or specificity, was much lower, 38.12% on average, and 46.75% using only IBI. Since Type II errors (false negatives) are preferable to type I errors (false positives) higher precision is more desirable than high recall. False negatives correspond to the status quo, where the anxiety is not automatically detected and a coping strategy is not triggered, while a false positive implies bothering the user by proposing a coping strategy that he doesn't need. Furthermore, long periods of anxiety are more relevant than shorter periods, thus missing to detect an isolated period of anxiety within a 60-second window is not critical, while a longer episode of anxiety has higher probability of being detected.

We performed an additional test using data from all subjects for training (80% of all segments were used for training and 20% for testing). This produced a small improvement in precision (81.48%) but a more significant increase in recall (51.16%). This provides evidence of differences in the physiological response of individuals to these stimuli, this was particularly true for the GSR signal.

7. LIMITATIONS

Although we gathered data from different devices, we only used two physiological signals to conduct tests and visual interpretation. Anxiety detection is a hard problem, and becomes harder under naturalistic conditions. Ground truth gathering is a time consuming task when working with cognitive states. It took us approximately 10 hours of work to annotate the videos and process each 30 minutes of data to establish ground truth. An alternative that should be explored

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4 is the use of digital means to facilitate the report of anxiety episodes by the participant, rather than using pen and paper
5 the participant could for instance hold a device and grasp with different strengths to signal anxiety.
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7 The relationship between caregiver and person with dementia is also complex. In this paper we conducted an experiment
8 with persons with no emotional attachment or long history to the person with dementia. Although the real situations might
9 differ from the results exposed, we showed an initial way to gather data from caregivers.

10 Further anxiety detection methods are also needed, in particular to develop general models that do not require training
11 using data from the user.
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13 8. CONCLUSIONS

14 We conducted a naturalistic enactment experiment to induce and detect anxiety states making use of wearable
15 technology. As confirmed by self-report and observation, the intervention was successful in eliciting anxiety among
16 participants while caring for a PwD. We proposed a method for obtaining ground truth in a NE environment through self-
17 report, observation and video codification. Our results indicate that our approach can be used to detect anxiety on the
18 caregiver in naturalistic conditions. We obtained a precision of 80% using only the IBI signal; this is consistent with
19 previous results in anxiety recognition in either in controlled environments, such as riding a roller coaster [25], or
20 conducting everyday office work [26], and using a variety of sensors. However, our main contribution relies on the use of
21 Naturalistic Enactment to elicit anxiety among caregivers. Gathering anxiety data under naturalistic conditions is an
22 important step in the direction of developing applications that can assist caregivers to cope with this condition. Once these
23 anxiety episodes are detected, the caregiver can be made aware of them and appropriate actions can be recommended
24 to deal with this, such as deep breathing or making the caregiver aware of the condition of the PwD. In [27] for instance,
25 the authors propose the use of micro-interventions to cope with stress that can be implemented on smartphones and
26 provide evidence of their effectiveness.

27 While our aim was to gather anxiety data under naturalistic conditions, we have limited our approach to participants
28 conducting one specific task, conducting a therapy with the PwD. A remaining challenge is to obtain reliable data while the
29 participant conducts everyday activities. An additional open problem is to determine how and when to propose a coping
30 intervention with the participant, and how to deal with false positives without disrupting the user.
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