Measuring Environmental Data and Physiological Parameters at Home to Assess the Caregiver Burden in Assistants of People with Dementia

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Abstract Measuring the behaviour and health status of informal caregivers of people with dementia can predict the personal well-being of the caregivers. Informal caregivers struggle to remain active during the daily life activities avoiding the care burden. For this reason, in this work, an analysis of both the environmental data coming from PIR sensors, installed in the home environment, and physiological parameters, directly measured by the user, is performed to highlight, unusual behaviors that can increase the stress level of the caregiver. In addition, daily survey and personal interview provide further information about the progression of the illness and the amount of the care burden. Coupling this information with the physiological quantities can provide an overall health status of the caregiver. Results show that the caregiver presents a decreasing trend of her daily self-reported health status associated with a change in the pattern of the domotic data. The questionnaire also exhibits

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a high correlation with body weight measurements (Pearson Coefficient of -86%) suggesting that the caregiver health status is limiting the normal daily activities, may be due to an increase of the care burden associated to a worsening of the illness.

1 Introduction

Behavioral and physiological measurements define the well-being, health and stress condition of caregivers [1]. Introducing Information and Communication Technology (ICT) solutions in the home environment can monitor the status of a patient for informal and formal caregivers that are outside the home [2] and the behavior and stress condition of the informal caregiver that lives with the patient. Sensor network are used to acquire data and signals of inhabitants and data processing can be performed to extract specific features as the care burnout. Several works indicated that caregivers of people with dementia are inclined to an increase of care burden [3]. The number of informal and formal caregivers of people with dementia are enormous and it is correlated with the number of people with dementia. The global number of people living with dementia was estimated at 43.8 million in 2016, an increase from 20 million in 1990. In 2050, this number is predicted to reach at 131.5 million [4]. This increase is coupled with a need of care which can results in care-related stress and burden among caregivers. Both professional and informal caregivers experience stress and repetitive negative emotions, not only at home, but also at work and outside [5]. The continuous demand and stress can result both in physical disease (e.g. cardiovascular, musculoskeletal) or mental disease (e.g. burnout, depression) [6], resulting in formal- and informal carers struggling to remain active during the daily life activities.

Most people with dementia live at home where they are dependent on informal caregivers for their daily care. In particular, female, spousal caregivers appear to be at risk of depression, anxiety and caregiver burden [6]. To decrease the negative influence of such critical home condition, measurements of the environment and health status may identify the decline of the caregiver well-being. At the same time understanding the factors that influence the caregivers' health state is fundamental for the development of effective support [7].

This paper is focused on an accurate analysis of the data and signals measured on an informal caregiver that lives with a person with dementia to identify changes in the behavior, physiological parameters and mental conditions. To measure the personal well-being of the caregiver, data provided by different Passive InfraRed (PIR) sensors installed in the home environment are investigated and they are associated to the physiological parameters acquired by the user three times a week for a year. A validation period of two months is performed using a daily survey and monthly interview to the user to study a correlation between the physiological parameters' trend and the behavior of the caregiver as the care burden increases with the worsening of the dementia.

2 Methodology

This paper aims at identifying the burden of a caregiver which lives and takes care of a person with dementia by measuring the behavioral change in the home environment and correlating it with the increasing burnout of the caregiver.

To monitor the personal condition of the caretaker, three main physiological quantities such as mean arterial pressure (MAP), heart rate (HR) and body weight (W) are acquired. Sensors' characteristics are reported in Table 1.

These devices are selected by the authors since a combination of the measured variables can be representative of the overall valuation of the general health status of the monitored user. In addition, these devices can be easily adopted by older people as they are widely spread among the daily routine of the user.

For this particular analysis, a family was chosen from a bigger pilot case that includes 8 apartments and 13 older users in a town in Italy [8]. This work is part of the Italian Smart Cities project "Health@Home: Smart Communities for citizens' wellness" (H@H).

The selected family is characterized from a couple of married people. The man (77 years old) is affected from dementia at the mid-stage. His wife is 71 years old and she is in a good health condition, not presenting any severe pathology. Every day from Monday to Friday, she brings him to the daily center for people with dementia at 9 am and she brings her husband back home at 4 pm. In the evening, during the night and weekends, she takes care of her husband alone in the home environment.

2.1 Monitored Parameters

The physiological parameters considered for the study are the body weight, heart rate and blood pressure. The physiological data are collected using a tablet with a customized User Interface (see Fig. 1).

The system architecture, data connection and Cloud database are described in [8–10].

Table 1 Technical specifications of the devices used by the caregiver for the physiological measurements

Device	Description	Accuracy	Resolution	Range
Taidoc TD3128B	Blood pressure meter to monitor diastolic, mean and systolic blood pressure and HR	Systolic: ± 3 mmHg ($\pm 2\%$) Diastolic: $\pm$ 3 mmHg ($\pm 2\%$) HR: $\pm 4\%$	1 mmHg (systolic, diastolic) 1 bpm (HR)	Systolic: 60–255 mmHg Diastolic: 30–195 mmHg HR: 40–199 bpm
Taidoc TD2555B	Body weight scale	± 0.3 kg ($\pm 0.5\%$)	0.1 kg	4–250 kg

Tablet

Blood Pressure Meter   Body Weight Scale

Fig. 1 The customized user interface for data collection, a blood pressure meter to monitor the blood pressure and heart rate and a body weight balance to acquire the body weight

The dataset is characterized from behavioral data coming from domotic sensors installed in the domestic environment and physiological signals collected during the daily measurements [11].

For what concern the behavior analysis, the data comprised of the signal outputs of three PIR sensors, installed in the living room, bedroom and bathroom (see Fig. 2).

2.2 Questionnaires Data

The questionnaire is divided in two parts.

The first part is a daily survey based on the SF36 and SF12 questionnaires [12, 13] and related to the physical activity and condition of the caregiver which filled the questionnaire every day for two months before going to sleep. For this specific analysis, one question, representing the global health condition of the caregiver is analyzed. The question is:

1. Did your health limit you in your daily routine?

The user can answer the question with 1 (representing that the user has been totally limited in doing daily activities from its health), 2 (the user can do its own activity but in a limited way) or 3 (the health status does not affect its health at all).

Fig. 2 Plan of the apartment and location of the 3 PIR sensors (placed in the living room, bathroom and the bedroom, respectively)

The raw survey is processed using a moving average technique that creates a series of averages of different subsets of the full dataset as described in [14]. This technique provides a trend in the person's behavior and aims at forecasting the well-being changing over time.

The second part of the questionnaire consists on a face-to-face interview made once a month for two months from an external assistant. The interview aims to investigate both mental and physical status of the caregiver and in turn, the caregiver gave an update of the disease status of the person with dementia.

2.3 Data Analysis

The information extracted from PIR sensors indicates whether the user has entered the room and/or is moving within the room. Therefore, data are processed by counting the number of occurrences of the sensor switch-on. In particular, PIR activations are hourly counted and then processed by aggregating the total number of activations recorded in a time interval of one hours. Then hourly aggregation is grouped together in 4 time intervals of 6 consecutive hours that represents: night (0–6), morning (7–12), afternoon (13–18) and evening (19–24).

The methodology has been applied considering a validation period of two months in which data are processed to evaluate if there are some differences in the behavior of the family unit. The discrepancy between the two months are evaluated on the basis of the total activation of the PIR for a specific time frame respect to the number of the activation of the overall two months period according to the following equation:

$$\% Activation_{m_i} = \frac{\sum Activation_{m_i}}{\left(\sum Activation_{m_i} + \sum Activation_{m_k}\right)} \tag{1}$$

where m_i refers to the i-th month while m_k is the k-th month. The numerator is the number of total activations of the selected sensor occurred in a single month and the denominator represents the total number of activations during the two months period.
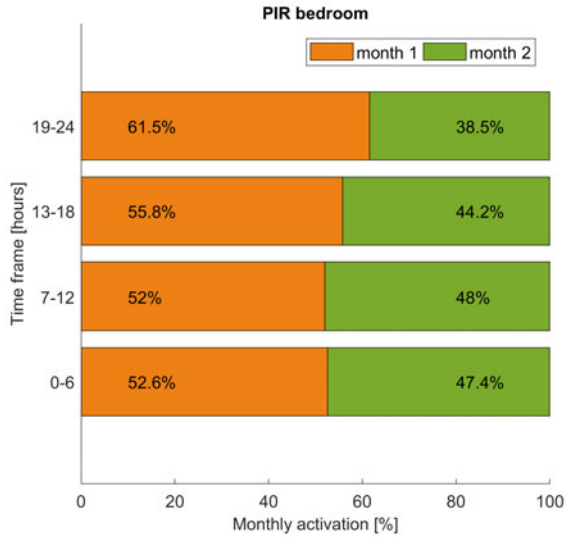
3 Results

In this section, some observations and results are presented. Data analysis provides the number of the total activations of the PIR sensors in the different time frame of the day for each month. Therefore, the variation of this quantities is analyzed.

Figures 3, 4 and 5 show the percentage of activation of each PIR (installed in the living room, bedroom and bathroom) for the two months over each daily period. In particular, the attention is focused on the PIR installed in the living room and bathroom. The activations of these sensors in month 2 are higher than in month 1

Fig. 3 Percentage of activation of the PIR installed in the living room through different time frame of the day, for the 2 months monitored for the validation phase
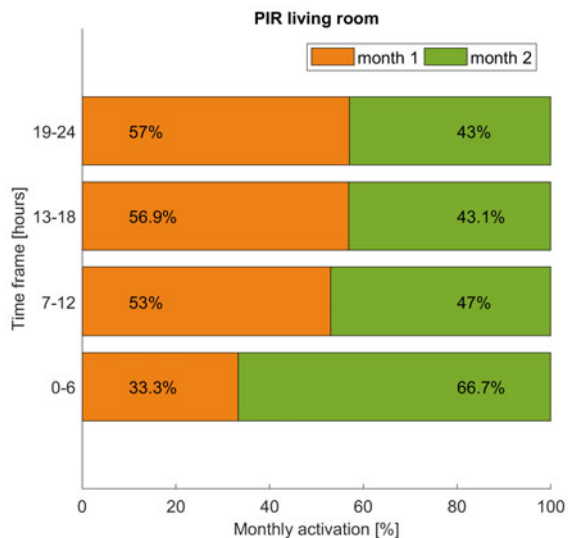
Fig. 4 Percentage of activation of the PIR installed in the bedroom through different time frame of the day, for the 2 months monitored for the validation phase

Fig. 5 Percentage of activation of the PIR installed in the bathroom through different time frame of the day, for the 2 months monitored for the validation phase
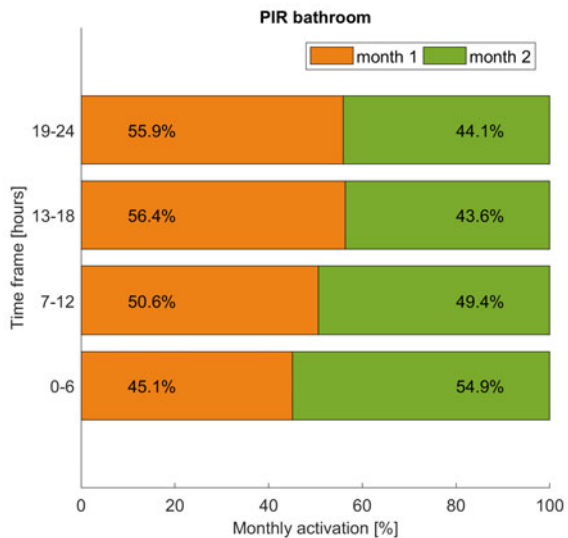
for the time slot 0–6. These results show how the family changed their nocturnal behavior.

In particular, the increasing of the activities in the living room and bathroom can be associated with a worsening of the dementia disease. This result is in line with medical findings in the scientific literature which highlights how the changes in the sleep patterns can be associated with the illness drop [13].

Fig. 6 Trend of the daily
survey provided by the
caregiver across the two
months of validation period
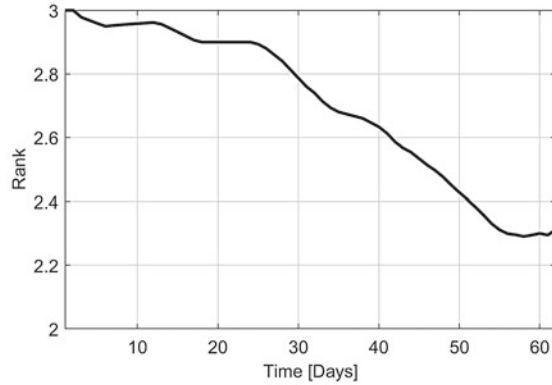
On the other hand, observing the time frames 7–12, 13–18 and 19–24 it is possible
to note that the activations number decrease: a possible explanation is that in these
specific time frames the house is only occupied by the caregiver since the dementia
patient is supposed to be at the health center. Moreover, during the interviews she
declares a repeated back pain that limits her daily routine.

The second observation is focused on the daily survey and monthly interviews.

Figure 6 shows the trend of the daily survey provided by the caregiver, processed
with a moving average technique, for the 2 months of validation period. A decrease
of the rank from 3 to 2 denotes that the caregiver perception of her personal health
condition is lower in month 2 than in month 1. This can be associated with the higher
nocturnal activity of the family in month 2. The decrease of the self-reported health
status is also correlated with the self-reported interview: the caregiver reported an
increased repeated back pain events during the second month.

In particular, from the monthly interviews, the authors extracted that the caregiver
is more stressed in month 2 than in month 1 caused from a back pain and a worsening
of her husband's conditions.

The last observation is related to the correlation of the processed daily survey with
the physiological parameters monitored 3 times a week from the caregiver using the
blood pressure meter and the body weight scale. Table 2 reports the results of the
Pearson's coefficient that indicates the existing correlation from the physiological
parameters (e.g. heart rate, mean blood pressure and body weight) and the daily
survey processed with the moving average technique.

Table 2 Pearson correlation
coefficient standardized from
0 to 100% computed between
the survey provided during
the validation period and the
physiological parameters
measured by the caregiver

Parameter	Mean arterial pressure	Heart rate	Weight
Pearson coefficient (%)	39	−46*	−86*

*p-val < 0.05

Fig. 7 Plot of the linear correlation between the weight measured by the caregiver and the respective self-reported health status provided in the survey. Note that there is a decreasing trend of the weight as the caregiver rank its day with a higher vote

To test the meaningfulness of the data, P-value (p) was set at 0.05 (significance level). When $p < 0.05$, the correlation between the data and the survey is statistically significant [15]. Table 2 highlights that the survey correlates most with the body weight ($R = -86\%$) of the caregiver.

Figure 7 suggests that an increase in the body weight is strictly connected with a decrease in the questionnaire rank (i.e., a decrease of the self-reported health status) which means that the caregiver health status is limiting the normal daily activities causing a more inactive and steady condition. The decrease of the caregiver health status may be due to an increase of the care burden correlated with the worsening of the patient's dementia state.

4   Conclusions

In this work, a heterogeneous sensor network installed in the home environment is used to monitor the behavior of a family (a person with dementia and his wife) and the health status of the informal caregiver to identify the caregiver burden together with questionnaires and interviews. In this paper, the authors process environmental data and physiological signals to understand the stress and health condition of the informal caregiver associated with the worsening of the dementia of the patient at home. In particular, domotic quantities acquired from PIR sensors installed in the home environment were monitored: the analysis shows an increasing nocturnal activity in the period 0–6 for month 2 of the validation period.

This condition can be associated with the degeneration of the illness of the patient, which results in a discontinuous sleep pattern that causes extended awake phases

during the night. For this reason, the caregiver presents an increasing level of personal stress confirmed by the daily survey and the monthly interview. In fact, there is a decreasing trend in the rank of the questionnaire that accentuate the decaying status of the health and an increasing care burden. Moreover, the interview reports how the caregiver itself is affected by some back pain due to the advanced age that contributes both to the limitation in the daily activities' routine and a major effort for taking care of the dementia patient.

More in detail, studying the correlation between the biomedical data and the questionnaire during the validation period, it is possible to observe that a decrease in the caregiver's self-reported health status representing a higher limitation in the daily activity of the caregiver is strictly connected with an increase of the body weight. The correlation between the daily survey and the body weight shows a Pearson coefficient of -86%. A possible explanation is the limited amount of the daily activity performed by the caregiver due to the caregiver health status and to the repeated stress condition associated with the caregiver's task.

This consideration comes from an accurate analysis provided by the association of multiple quantities which are domotic data, physiological data and information provided by the caregiver. Therefore, weight measurements can be interpreted as a partial index of the caregiver health status that as to be linked to the progress of illness. In conclusion, this paper shows that with a heterogeneous sensor network installed in the home environment is possible to extract the behavior and health status of people inside the home and evaluate the behavioral variations in different period of time. The aggregation between environmental data, physiological parameters and questionnaire provides relevant information to identify the caregiver burden.

Future works will be focused on increasing the number of participants to the experimentation to test the methodology and improve the statistical analysis. Patients at different stages of dementia and their caregivers could be included in the study and a longer period of daily report could improve the results.

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