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Towards a SaaS application providing an ethical support for human caregiving of people living at home

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Abstract—With an aging population, we have to prepare for a growing number of people with a loss of autonomy. Many papers focus on digital solutions for assisting and monitoring those people. In contrast, solutions are missing for monitoring human caregivers. This paper suggests using digital solutions towards a support for ethical reasoning through data collected among various participants including the recipient, the caregivers, the family and may be the physicians. Our purpose is thus to ease the cooperation among the participants. We start from an existing SaaS application marketed in France called SIPAD Connect. This paper proposes several additions in order to better support cooperation. First, new data and indicators are suggested for the recipient. Second, the participants can give their opinions for those data and indicators. Those opinions can be computed in order to raise alerts. The proposed alerts include not only the situation of the recipient but also feedbacks aiming at improving the SaaS application. Thus, both the cooperation and the computation open discussions regarding the recipient, the efficiency of the care and the quality of the SaaS application.

Keywords—Home caregiving, SaaS, ethics, computation, AI

I. INTRODUCTION

Europe will face a significant increase in the number of people facing a loss of autonomy, in proportion of total demography. People with a loss of autonomy generally prefer to stay at home or, as an alternative, seniors' residences. Aging in place have significant benefits regarding health care costs [1], quality of life [2] or maintaining social networks [3] to name a few. For this purpose, different approaches are available. First, the family provide some care. Second, automation and connected devices can assist the person. Third, help at home provide some assistance (e.g. for eating and cleaning), and if conditions are met, through social grants. Despite all these approaches can be mixed, our study takes place in the third situation where caregivers regularly come at home for different assistances. However, in such a context, the relatives and sometimes the social services or the physicians are also involved in the care. Note that caregivers can name either family caregivers, such as older people's kids, or professional caregivers.

Since dedicated private companies offer such caregiving in the context of a social grant, the social services but also the family need interactions with the recipient. Dedicated SaaS applications are proposed to help the connection between the different stakeholders. SIPAD developed such a Cloud software. The SIPAD SaaS application, called SIPAD Connect, has several advantages related to data that are collected by professional caregivers regarding the different tasks of care. We recall that a SaaS (Software as a Service) application is based entirely on the Internet. In other words,

the application can be accessed by users from any device, provided an Internet connection. The application is based on databases and isn't installed directly on users' device.

This paper describes the approach currently followed in the context of Pierre Bouchet's Ph.D. thesis. The general objective is to extend the SIPAD's SaaS application towards a service that supports an ethical discussion. In contrast with a complex ethical reasoning model [4], lightweight services offer a flexible way of cooperation. Those services take full advantages of the participant's opinion in order to provide graphics and alerts through a dedicated computation science. Moreover, the participants also give an opinion regarding the proposed computations. Thus, the cooperation is extended in direction of a meta-evaluation of the computations. Dedicated alerts and notifications invite the participants to cooperate for analyzing the conflicting evaluations. In addition, alerts and notifications invite SIPAD to revise and update the model of data or the computations to cope with inconsistent results.

II. STATE OF THE ART

A. Current software products

Since the population of older people is expected to increase during the next decades, both in France and abroad, then the number of people facing a loss of autonomy will increase too. It is necessary to find solutions in order to allow people to stay at home as long as possible.

As previously said, various approaches are available to cope with a loss of autonomy. We can mention family care as well as Smart Home Monitoring Systems (SHMS) that covers all sensors-based solutions. SHMS technologies aim at monitoring people with equipment running algorithms based on Artificial Intelligence (AI). Sensors can take different forms to name a few : (i) in-home passive sensors based on infrared, (ii) body-worn sensors such as accelerometers, (iii) video monitoring coupled with image recognition or (iv) sound recognition.

All these solutions are widely studied in literature [5]–[7]. Note that a new multidisciplinary domain has emerged called gerontechnology [8] which covers all technologies matching with gerontology. The aim of SHMS is to detect any abnormal situation and especially falls or behaviours as soon as possible in order to quickly intervene.

Our study proposes another approach that in some situation could be coupled with SHMS. We are setting in a context of home care with associated professionals. We found no thorough research as there is for SHMS regarding the use

of AI and digital solutions, besides an application allowing people to order care services [9].

B. Home care for the loss of autonomy

In order to deal with loss of autonomy at home, several measures can be taken [10]. One may need homecare support, which assists people on daily tasks such as laundry, shopping, cooking, personal care and so on. It is based on an assessment of recipient's care needs. Then it is possible for people to adapt their homes to their loss of autonomy, e.g., by buying grab bars, mobility aids and other technical assistance.

Another kind of home care service is telecare. It is quite similar to gerontechnology as telecare detects when a problem occurs and is connected to a call centre. Next, call centre will contact either emergency teams or relatives, depending on the gravity.

To date, digital technology is quite lacking for professional use, besides SHMS. Few propositions exist for a digital tool intended for professional caregivers in order to help them for their interventions. In addition, no application exists for collecting data from professional caregivers and supporting cooperation in direction of an ethical reasoning.

C. Ethics of the care for the loss of autonomy

Hood et al. have proposed a new vision of healthcare using new technologies in 2004 and this global vision was taken up various times since [11]–[13]. They brought forth the notion of P4 medicine, i.e. a medicine that is:

1. Predictive, e.g. predicting falls [14].
2. Participatory. Allowing patients to participate actively in the decision making.
3. Personalized. Data is collected and processed from one's everyday living.
4. Preventive. The system is preventive as measures can be taken to limit the predicted risk.

The participation of recipient to the decision making is a part of ethical reasoning as it is at the core of nursing practices [15]. Ethical reasoning is a global framework that has been studied and adapted for medicine [16], [17]. Yet, quite a few models of ethical reasoning has been developed for home care [18]. A global approach was proposed in 2018 for the care of disabled people based on ethics [4]. But these approaches were not turned towards digital. We propose a new approach for home care that conforms P4 medicine and deals with multiple existing ethical risks regarding the use of AI.

D. Discussion

Pilotto et al. have suggested in 2018 to use technologies not as disconnected tool to follow some specific tasks. They suggested to integrate technologies directly into the care system, aiming at a personalised approach [14]. As we will detail below, our approach is integrated into home care existing practices.

Rubeis has pointed out four ethical risks about gerontechnologies based on AI [19]. He suggested to name them “the four ds” to contrast with P4 medicine. The four ds stand for:

1. Discriminatory: risk related to stereotypes and categorizations liked used in AI frameworks.
2. Dehumanized: risk of disempowerment with tasks decided by AI in addition to a legal risk.
3. Disciplining: risk of a conformance to a “norm” set by AI.
4. Depersonalized: risk that an AI system will be considered more trustworthy than personal experiences.

Other ethical considerations, essentially consent, privacy and black box effect have been studied such as in [20]–[22]. However, those ethical considerations were focused on SHMS, even though they may apply to our context.

Thus, the risks related to an AI deal with deontology and ethics. In contrast with a pure AI system, our approach is consistent with P4 medicine but provides a mean of ethical reasoning through the cooperation of the participants. The proposed decisional assistance is always evaluated with complementary human opinions. It also addresses conflicting objectives of care and ethics as well as assessments.

III. THE CURRENT SIPAD SAAS APPLICATION

A. The SaaS environment

SIPAD¹ is a French company which main objective is to interconnect all relevant stakeholders. It connects professionals of home help, telecare, medical equipment with the recipient and its relatives. In other words, SIPAD has a multidisciplinary approach of care. The target not only is older people but also disabled people of all ages. It addresses people living at home. The very essence of SIPAD is to encourage independent living at home with the support of professionals and family, as long as possible. SIPAD offers a digital logbook and others features as described further.

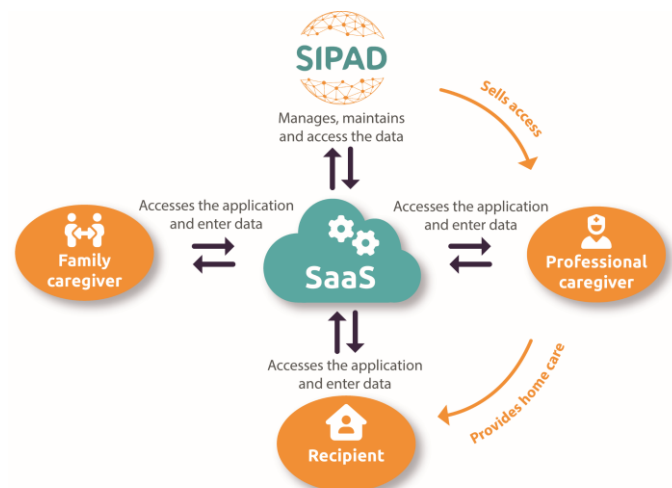


Figure 1 : SIPAD functioning in a SaaS environment

SIPAD Connect is a SaaS solution described in Figure 1. SIPAD provides access to a database for professionals, family and recipients. Note that data, according to L.1111-8² of the Public Health Code, is hosted as Health Data Hosting which is the governmental French label to guarantee the security of

¹<https://sipad.com/>

²https://www.legifrance.gouv.fr/codes/article_lc/LEGIARTI000033862549/ (in French)

health data. Professionals, family and recipients have different levels of access depending on their status. Currently, only professional caregivers can rate the recipient's health. The approach of SIPAD is complementary to SHMS.

B. The available Data

SIPAD Connect is collecting several different types of data which are used by home care professionals to monitor recipient's health and to organize their interventions. The recipient and his family can access those data.

The first collected data are related to the tasks performed by caregivers, both professional and family. Those tasks are gathered in the so-called "logbook". This allows both information sharing between stakeholders and actions history. A total of 149 tasks is available. Each one of them is labelled as one of the following 15 categories:

1. Mobility aid (help for moving in and out of bed or chair, walking, etc.)
2. Personal hygiene aid
3. Cooking and feeding aid
4. Indoor activities (chatting, reading, playing, etc.)
5. Outdoor activities (shopping, going to appointment, going to museum, etc.)
6. Housekeeping for kitchen (wash dishes, wash floor, tidying dishes, etc.)
7. Housekeeping for sanitary (cleaning toilets, wash the floor, etc.)
8. Housekeeping for bedroom (changing of bedding, ventilate the room, etc.)
9. Global housekeeping (vacuuming, wash the floors, etc.)
10. Gardening
11. Laundry care
12. Administrative support
13. Medication intake support
14. Pet support (going to the groomer, feeding, etc.)
15. Logistical tasks (switching heater on, changing a bulb, etc.)

Another type of data is related to the recipient health. Each professional caregiver provides a quantitative multidimensional evaluation that is undertaken at each intervention. It is not a significant workload as the professional caregivers already have to assess it on paper. So, this is basically a digitalization of current practices. The evaluation is related to 7 items:

- Sleep
- Appetite
- Mood
- Coherence
- Serenity
- Autonomy
- Hydration

Each of these items are evaluated on a 4 points Likert scale. To be more intuitive, the possible answers are represented as weather icons: **storm**, **rain**, **veiled sun**, **sun**. We consider that sun is better than veiled sun which is better than rain which is better than storm. An even number of levels has been chosen to prevent users from choosing a central measure, as it would be similar to a neutral value. In addition, we consider that 4 levels is a decent compromise between sensitivity and reliability. Indeed, as the number of levels increase, the sensitivity will increase too, so we do not want to have many levels. Yet, if we decrease the number of levels then we decrease the reliability. Therefore, we have to choose a number of levels that is neither too high nor too low. This dilemma is similar to the well-known "Bias-variance trade-off" in machine learning.

The 7 items enable professionals to monitor the recipient's health in order to prevent any dramatic decrease that could lead to event such as falls or hospitalizations. For convenience, we shall use henceforth a short term for these data, namely "weather".

Others features such as spotting needs and secured messaging service are available. These functionalities allow stakeholders, especially professionals, to exchange on any particular event. For instance, if the recipient needs a medical appointment or is absent for some reasons, then it is possible to prevent all the other stakeholders via the application.

All these data can be exploited through miscellaneous machine learning algorithms. For example, changepoint detection models are proposed for the weather data. It notifies the caregivers about the dramatic fall of an item, allowing both professionals and family to quickly react. Note that changepoint detection models also are used in SHMS [23] despite home care is not considered.

C. The current limitations

To date, current limitations are multiple. First, there is no way for recipients to express their opinions directly in the application, especially disagreements. For example, if a recipient doesn't agree with the rating of a professional caregiver about sleep, then he cannot express his disapproval. In our example, the only way to do so for the recipient is to interact directly with the caregiver. That is why an *a posteriori* rating is needed, which will allow the recipient to express his opinion at any time.

Another limitation is that there is no way for the professional to give his opinion about the data quality. Indeed, a professional caregiver could be sceptical when he assesses one of the 7 items.

Finally, the current indicators are not put in perspective with the context of the recipient. It is known that the context has a direct impact on health [24]. For instance, consider an older people with no proper material to move around in home. If there is no information collected about the fact that he cannot move around freely, how to interpret an alert about his low moving activities? This alert makes sense only against the context. So, an alert has a particular significance regarding the global situation of the recipient.

IV. TOWARDS A SET OF TOOLS SUPPORTING ETHICAL REASONING

A. The general approach

In order to support an ethical reasoning several features have to be added. All the features must be directed towards an ethical processing and must provide a support for an ethical discussion. Indeed, we can distinguish an ethical processing, i.e. is the way the application collects and processes the data from an ethical discussion that is at the heart of nursing practices. To reach the goal of an ethical processing that cope with the considered ethical risks, we should keep in mind that:

1. All indicators must be explained to stakeholders. Given that everyone has different understanding ability, it is essential to build a kind of manual explaining the computations. This can take the form of a switch where people disable graphics or indicators when they don't understand it. We aim at an inclusive tool, based on each participant's ability. Note that explaining computations lower the risk of a discrimination.
2. No automatic decision has to be taken by an AI or the digital system. Every decision is associated with humans' consideration. The proposed approach is a decision aid that collects, centralizes and processes data. This is a way of fighting against the risk of dehumanisation and depersonalisation.
3. The General Data Protection Regulation is a regulation on data protection in the European Union. In this context, law and ethics require to inform recipients about which data is collected and how the data is treated. Moreover, law and ethics require to collect the recipient's consent to provide an access for the family caregivers and to collect sensitive data.

B. New data and indicators

First, new data and indicators are proposed for the items. In additions to new assesses, opinion data and alerts are available. Figure 2 shows an example of dashboard for the sleep item. R Shiny³ was used to develop it. In addition to the professional assess, the recipient and the family can give an assess for the sleep too. The opinion data enables each participant to give a rating for his own assess. The idea here is to avoid dehumanisation, and also disciplining. Indeed, a participant can express that he does not trust his assess or the way assesses are collected. Finally, alerts of conflict propose new indicators for detecting different kinds of inconsistencies.

As shown in Figure 2, the recipient can rate his own sleep on the same scale used by the professional caregiver. Thus, a disagreement can be observed. Participants also rate their confidence in their own assessment through a binary assess using in this example thumbs up and thumbs down

system. Confidence allows them to take some distance with the data. For example, the professional caregiver can be sceptical about his sleep rate for various reasons. All these elements then generate alerts when conflicts occur.

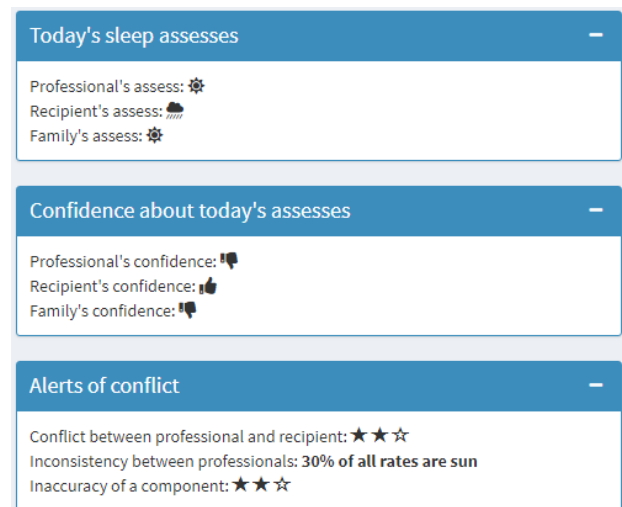


Figure 2 : example of dashboard and alerts using Shiny

Thus, advanced information sharing is available such as required to avoid redundancies in acts and to help discussion about sensitive care issues [25]. Indeed, the idea is not to track professionals but to propose a way for all stakeholders to provide better evidences for the value of data.

Second, new data take the context of a recipient into account including an “environmental context” and a “social context”. The first one includes all elements regarding the home and its nearby: proximity to services like pharmacy or supermarkets, details about home such as the presence of medical equipment or the accessibility. The second kind of context includes details about cognitive abilities, family life, finances, or life style. From the context, we can then compute indicators such as a service density which could be the number of services in a given radius around recipient's home.

Third, cooperation data are proposed. The first level of cooperation is the ability for participants to give their ethical or care objectives. For example, a care objective of a recipient might be to eat with the caregiver. An ethical objective for the recipient might be to respect his will. A care objective for the caregivers might be to prepare the meal. An ethical objective for the caregivers could be to adjust to the disability of self-determination. Those two ethical objectives can be conflicting.

The ability of rating for recipients can be done on two levels. The first level is about rating the fulfilment of predefined objectives, i.e. rating if they consider that their objectives have been fulfilled. The second level is about trust about these data. In the same spirit, family and professional caregivers are allowed to rate objectives' fulfilment as well as their confidence with the data they enter. For the sake of

³ Winston Chang, Joe Cheng, JJ Allaire, Carson Sievert, Barret Schloerke, Yihui Xie, Jeff Allen, Jonathan McPherson, Alan Dipert and Barbara

Borges (2021). shiny: Web Application Framework for R. Rpackage version 1.7.1. <https://CRAN.R-project.org/package=shiny>

brevity, this paper does not give a dashboard for the context and cooperation.

C. Computation of alerts

1) Alerts of conflicts between caregiver and recipient

The first kind of alert is between caregiver and recipient. After giving their opinions, the tool computes the level of disagreement between the recipient and his professional caregiver. This is obviously computed for each recipient with his own caregivers. It would be a nonsense to compare caregiver's agreement with recipient's one when they are not linked.

The discrepancy measure depends on the rating scales. If both agreements are on the same quantitative scale, then a traditional Euclidean distance or mean squared error are possible, among others. However, if they are free messages, then Natural Language Processing (NLP) is involved to extract one's opinion before computing discrepancies.

In our example shown in Figure 2, a caregiver rates sleep as "sun" while the recipient rates it as "rain". In this example the disagreement is quantified through stars as a normalized distance. Since professional and recipient provide two levels of difference, two full stars are displayed while one is empty. Moreover, this alert can open a discussion for analyzing the reasons of conflict in order to have a holistic approach.

2) Alerts of inconsistency between caregivers

Global statistics can be computed regarding caregivers' rates. We recall that we don't aim at rating professionals' habits nor to track them. Instead, we aim at creating discussions when anomalies occur.

The idea is to put in common all the evaluations from the caregivers, whatever the recipient is, to detect abnormal rates. The abnormality can be judged by the quantiles and other distribution's measures in a similar way to the philosophy of the p-value and type I error in statistical tests. In statistical tests, a 5% level is commonly considered significant because a p-value lower or equal has only a probability of 5% to occur. Note that the threshold is not fixed and can be different from 5%, depending on the acceptable risk one is ready to take on type I error.

Let's take an example related to home care. Consider a caregiver rating today's sleep as "sun" while only 2% of all caregivers rate "sun" for this recipient. In this case, rating sleep as "sun" has a probability of 2% to occur and yet it did. Given that 2% may be seen as a very low probability, there is a reason to notify about a possible inconsistency of caregiver's measure or at least a necessity to investigate. In our example displayed in Figure 2, 30% of all professional rates for this recipient's sleep are "sun". Given that today's measure is also "sun" it cannot be considered as inconsistent because it is not likely to be abnormal, unless 30% is considered by stakeholders to be an acceptable compromise for type I error.

3) Alerts of obsolescence of a component

This kind of alert is intended to warn stakeholders when a measure is inefficient or obsolete. The measure in our example in Figure 2 is sleep. Using the same logic that for inconsistency between caregivers, we study the distribution and other statistics.

If statistics show the stakeholders that the measure is mostly not informative or even missing, then the system shall send an alert to them. This is a logic of a continuous improvement process where tools are able to criticize themselves. It is possible to associate it with the opinions of the participants about the measure.

For our sleep example in Figure 2, the system computes an alert for that component. Family and professional caregivers have declared to not be confident about their sleep's rate of the day due to a high level of uncertainty. The fact that they are not confident is provided by the thumbs down system in the second tab in Figure 2.

In the third tab, two stars over three are filled. It is because two participants over three are not confident about their own assesses. The more stars are filled, the more today's measure is considered to be obsolete. The high level of uncertainty in today's sleep rate may either come from a misunderstanding of how to rate the recipient's sleep or even from a wish to not rate the sleep. This kind of alert leads next to a discussion between all stakeholders that will conduct to not rate the sleep anymore.

4) Discussion facilities

Discussion's tools already are existing in SIPAD Connect. Thus, the participants can discuss through a messaging system in accordance with the philosophy of a SaaS application. However, a deliberation tool can be added to support different kinds a reasoning like casuistic (study of similar cases), scenarios (with a vote system among at least 3 possibilities), evidential reasoning (evaluate multiple conflicting criteria) among other things. The idea is to have a pragmatic approach where all kind of thinking and reasoning can be supported. Another advantage of a deliberation tool is that it allows to have an history of decisions. It may be requested to justify the choices made afterwards or to compare with similar deliberations.

For instance, an alert opens an online deliberation about the disagreement between the recipient and the caregiver views about sleep. During this discussion, the caregiver obtains some medical information that explains why the recipient is used to sleep bad. In this case, the participants decide to not rate anymore the sleep due to this specific context.

V. DISCUSSION AND CONCLUSION

The growing number of older people and its associated loss of autonomy represents a challenge for the next decades. Many technologies have been developed based on sensors through the Smart Home Monitoring System but only a few tackle home care and its associated professionals.

This paper proposes a new approach supporting ethical reasoning. This is an ongoing work where various computational statistics must be experimented on real data. It aims at collecting data related to home care that does not add excessive workload. Presented suggestions tend to have a P4 tool based on the definition proposed by Flores et al., i.e. (i) predictive, (ii) participatory, (iii) personalized and (iv) preventive while taking into account the “four ds” ethical risks [13], [19]. Furthermore, ethical statements such as transparent modelling and decision making are supported through a human control. Our purpose is to facilitate cooperation, discussion and exchange of information. The tool does not intend to unilaterally take decisions nor to say the truth. Instead, it takes data and computes indicators to help the participants in their discussions.

One risk of our approach is related to alerts. The main pitfall with the proposed alerts is to find an acceptable compromise. If the false positive rate is too high, a consequence is that people will be less likely to believe in future alarms. Which makes them useless on the long term. So, there is a dilemma of communicating vessels between too many false positive alarms and missing a real problem. Moreover, one should keep in mind that the choice of a discrepancy for computing alerts and distances is highly linked to a point of view. Depending on the choice, the measure highlights only a piece of information and seldom captures the whole underlying dynamic.

Another limitation with proposed alerts is that they are based on global behaviours to determine the cut-off between normality and abnormality for personal applications. The generalisation is the major trade off with AI in our context [20]. That is why we suggest only using human-centred decisions.

Finally, our approach faces a problem of complexity in decision making with conflicting views and ethical objectives. The idea is to let the method of deliberation opened. Maybe in some situation an external method of deliberation can be used like a physical meeting. In such a case, the decision can be simply included in the system through a dedicated comment.

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