

CareKeeper: A Platform for Intelligent Care Coordination

Haridimos Kondylakis
FORTH-ICS
Heraklion, Greece
kondylak@ics.forth.gr

Dimitrios G. Katehakis
FORTH-ICS
Heraklion, Greece
katehaki@ics.forth.gr

Angelina Kouroubali
FORTH-ICS
Heraklion, Greece
kouroub@ics.forth.gr

Kostas Marias
FORTH-ICS
Heraklion, Greece
kmarias@ics.forth.gr

Giorgos Flouris
FORTH-ICS
Heraklion, Greece
fgeo@ics.forth.gr

Theodoros Patkos
FORTH-ICS
Heraklion,
patkos@ics.forth.gr

Irini Fundulaki
FORTH-ICS
Heraklion, Greece
fundul@ics.forth.gr

Dimitris Plexousakis
FORTH-ICS
Heraklion, Greece
dp@ics.forth.gr

Abstract—Informal care is fundamental in the wellbeing and resilience of elderly and people with chronic conditions. However, solutions for the effective collaboration of healthcare professionals, patients and informal carers are not yet widely available. CareKeeper builds on a state-of-the-art personal health system, augmenting it with Artificial Intelligence and Big Data technologies, to boost informal care coordination. In this paper we report on the design of the platform with the aim of providing a light-weighted communication solution to support practical challenges about sharing the responsibility of caring, such as the frequency of visits, support to routinely activities and timely intervention in case of emergency and need.

Keywords—Informal Care, Coordination, Intelligent Platform

I. INTRODUCTION

Informal care is fundamental in the wellbeing and resilience of the elderly [1]. However, solutions for the effective collaboration of healthcare professionals, patients and informal carers are not yet widely available and focus usually on information exchange between patients and health personnel [2][3]. This results in duplication of efforts, costs and overall heterogeneous accessibility of caring [4]. Recent approaches so far are fragmented, focusing usually only on a specific disease, or on connecting patients with healthcare professionals, neglecting to some extent the role of informal caregivers [1].

In this paper we present the design of the CareKeeper, a platform that builds on an Artificial Intelligence (AI) and Big Data-enabled, high technology readiness level, state of the art personal health framework (PHR-C) [5], to enable informal care coordination. PHR-C has been implemented through various R&D projects focusing, amongst others, on the management of pain [6], stress [7], COVID-19 [8] and cancer [9]. CareKeeper services offer intelligent communication and effective management of appointments, tasks, and emergencies for patients, professionals and informal caregivers, exploiting advanced AI algorithms for supporting routine activities. More specifically the CareKeeper platform includes:

- A mobile app for patients and informal caregivers and a website for healthcare professionals.

- An intelligent dashboard with visualizations about patient status based on available data.
- An AI predictive module that exploits personalized risk detection and assessment models to present the predictions to formal caregivers.
- An AI enabled calendar for recording, managing and visualizing care activities. The calendar includes intelligent scheduling and rescheduling mechanisms. It takes into consideration the diaries of involved parties, along with a number of predefined strong and weak preferences, to recommend suitable dates for scheduling health care events and meetings with the physician.
- An emergency module enabling the timely intervention of both formal and informal carers.
- An information sharing module enabling patients to have the control to share all, part, or none of their information with others.
- A communication module enabling patients to communicate with formal and informal caregivers.
- An interoperability module compatible with multiple standard formats and protocols such as FHIR¹ and JSON-LD².

To the best of our knowledge, CareKeeper is a unique platform extending a powerful personal health record platform towards the coordination of care. The remaining of this paper is structured as follows: In Section 2 we present the CareKeeper solution and in Section 3 we present related work. Finally, Section 4 concludes this paper.

II. CAREKEEPER SOLUTION

CareKeeper builds on an existing personal health system and addresses the specific challenges involved in providing a complete Informal care coordination system. All modules besides the AI-enabled calendar are already available. A high-level architecture of the solution is shown in Figure 1 and consists of the Application Tier, the Business Logic Tier and the

¹ <https://www.hl7.org/fhir/>

² <https://json-ld.org/>

Semantics and AI Tier. In this section, we describe each one of those layers in detail.

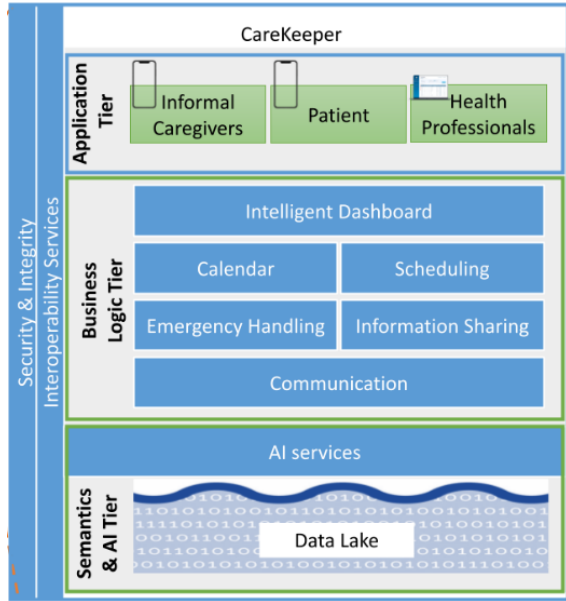


Fig. 1. High level architecture of the proposed solution.

A. The Application Tier

The Application Tier components in our solution are the mobile apps for patients and informal caregivers that run on the Android and iOS smartphones, and the website for healthcare professionals which allows intelligent patient data visualization and user role management. In addition, the services communicating with the mobile and web apps are implemented as individual RESTful services in full compliance with the proposed client platforms. The app for health professionals can be easily accessed through a hospital portal if such a portal is available.

B. Business Logic Tier

Intelligent Dashboard. All patient information collected through the platform is shown to the physicians through an intelligent dashboard. We have to note that the intelligent dashboard can also be used for visualizing external, linked datasets, providing uniform access to the patient data. Uniform access to patient-generated data, adds a new dimension of well-being. Also, it enables better (more accurate) assessment of the risks and benefits of personal actions, at different time granularity (e.g. patient may describe side effects and symptoms when they happen), in a different context (patient at home) and on a greater time span. The intelligent dashboard showcases statistics at various granularity levels (for example for all patients that have shared their data, for a single one or for a specific set), and visually provide an overview about patient calendars. Also, an important feature is the visualization of the potential risks patients’ face which have been identified by the risk models. Besides health professionals, an version of the intelligent dashboard is also available for the patients. Summary graphs depict the overall health status of each individual patient, the level of compliance, the general quality of life, health

indicators (e.g., weight, body mass index, blood pressure) and others. These are presented as the latest health news of the patient aiming at raising self-awareness. In addition, those graphs can only visualize a selected period of time. For example, users are able to see their general health status in the last year.

Calendar. The patient diary is primarily organised in a calendar mode. It supports day views, month views and year views and timeline views. The day view visualises the user activities and behaviour within each day. The data type may include activity, location, food, sleep, mood, symptom, condition, treatment (medication), laboratory (blood pressure, glucose), alcohol, smoking – to name but a few. Data files (such as an image or a text file) can be also displayed in the diary. Each data item is accompanied by icons that allows the user to access the data visualization tool as well as a series of operations such as data sharing, exporting and explanation, commenting, etc. In month and year views the users can see the highlights of their health-related events, which could be a hospital visit, health examination, major improvement of health behaviour (e.g. compliance, hospital release). Filters are used to select/ hide different types of the data during visualization. The timeline is be used as another display mode for the data. Within the timeline mode, all the data are be placed along a time axis to allow users to see the dynamic evolution of the data. Similarly, filtering is allowed to select/ hide the display of different data types.

Scheduling and Rescheduling. A proper solution to the appointment scheduling/ rescheduling problem is crucial for improving the satisfaction of both patients, carers and doctors, contributing the improvement of the quality of care. This service takes into consideration the diaries of all involved parties, along with a number of predefined strong and weak preferences, in order to recommend suitable dates for scheduling health care events and meetings with physicians. The rescheduler is triggered when alerts about unexpected or emergency events require changes to the original planning. In such cases, the rescheduler takes into consideration the need to minimise changes, in addition to the requirements specified for the scheduler. Given that different cases have different priorities and that changes or cancellations may be frequent, a solution needs to accommodate a number of requirements in a timely manner. This is typically a complex combinatorial problem, possibly involving optimizations. Moreover, as the output and final adaptation of schedules is made by human non-AI-expert users, the whole process is explainable and easily configurable, according to needs. This component is still under development.

Emergency Handling. This module handles emergency situations that are either automatically detected by the models or triggered by the patients and/ or their informal caregivers. As such, the AI models (described later) automatically trigger emergency alerts which will immediately notify formal caregivers (assigned nurses and doctors) calling them to contact the patient. Besides the AI models, the communication center has an emergency button available that enables the patient to call for help. This module allows the configuration of automatic messages configured with the appropriate content, specific recommendations, and type of channel such as via sms, email, mobile notifications etc. Finally, besides automatically sending a message to the health personnel, patients or carers can use the emergency phone numbers available through the application.

Information Sharing. Patients have the control to share all, part, or none of their information with their informal and formal caregivers at any time. CareKeeper also allows caregivers to follow up the situation and location of the patient during the hospitalization. Tracking of the patient condition and position is communicated through this module. All information about patient status is directly depicted in visuals that can be accessed by family members and formal caregivers. Patients have the control select who can see their data and status. They can share data with another individual or class of individuals. Patients are able to (a) give to a specified person time-limited read-only access or (b) give access to all members of a group (e.g., a primary care practice). The doctors or patients themselves are able to insert targets and their reminders in the diary – this could be, for example, a medicine needed at a specific time in the diary; a hospital visit scheduled on a specific day; or recommendations such as physical exercise [10][11].

Communication. Through this module, patients communicate with formal and informal caregivers, including family members, friends and acquaintances based on personal preferences. In addition, a patient question can be answered using a messaging system rather than a visit at the physician's office. The proposed solution sets meaningful restrictions for the communication, for example, a patient cannot contact a physician at any time or for any reason. This module includes a dashboard to visualize a summary of patient data or a detailed view of self-reported outcomes, and usage of the system. Based on automated expert-based decisions, the system suggests to physicians possible actions to support patients (i.e. call them by phone, or send them specific instructions via app). Patients with concrete questions can access the "user help desk" section that contains comprehensive categories and questions based on patient individual profiles. The patient can issue a question or select questions from existing categories. Then the system will provide possible solutions, explanations, etc. and ask the patient whether the information has been helpful. If the patient indicates that the problem has not been resolved, the system offers a message window where the patient can describe the problem, send a parameter or a report. Clear indication informs patients that this message will be sent to the treating physician and responded as soon as possible. The physician, upon login, is presented with a list of messages, which patients have sent since the last login. Messages contain the message subject, text, and attached information if available (e.g. a reading of a parameter or a report). When replying, the physician is offered with the possible standard message templates e.g. "Appointment needed", "Test required", "Goal needs to be adjusted", etc. Message templates are thus categorised for the physician to quickly select the appropriate response format, and pre-filled information whenever possible based on the analysis of the patient message. The physician can complete the message and either send it to the patient or contact a nurse with specific instructions about the patient.

C. AI Tier

AI predictive models: The platform is able to use and trigger existing external models potentially provided as a service, and present the predictions to the formal caregivers. As a proof of concept, we have introduced the Diabetes predictive use case, a model already in the market from FORTH, deployed

and used for predictive modelling of glycaemic status for diabetes management. The idea is that short-term prediction of glycaemic dynamics is essential to improve Diabetes self-management. As such a personalized, clinically validated, adaptive, real-time data driven computational solution will be deployed [12], identifying the different modes of the underlying glucose metabolism and eventually prevention, of hypoglycemic events. However, this is only an example model showing how external such services will be able to be connected to the platform.

D. Semantics

Data Lake & Interoperability. All data produced by the proposed solution are stored in a semantically enhanced data lake, where additional metadata were provided based on the available information [13]. In addition the proposed solution ensures interoperability with existing systems and with other devices that are necessary in order to capture certain clinical parameters [14]. The platform is compatible with multiple standard formats and protocols such as FHIR and JSON-LD. We have deployed a FHIR Server responsible for storing all medical data and patient documents that are consumed by the PHR-C. The FHIR server provides a RESTful API that defines a set of common interactions (read, update, search, etc.) performed on a repository of typed resources. PHR-C enables access to the clinical data external resources that are shared with a FHIR Server. As such, a user can retrieve his/ her data stored into the FHIR Server by submitting a read/ search request using the corresponding FHIR REST API calls. The FHIR specification is integrated to allow for the interoperable operation and communication of PHR-C with other healthcare systems built upon FHIR. Remapping is performed to the underlying modules and healthcare data that PHR-C handles to FHIR resources. This allows a user using CareKeeper to view access data from external healthcare systems implementing the FHIR specification, thus offering a global view of his/ her health operation over possibly multiple health apps. Further all access to the information is regulated by strong encryption, authentication and authorization and as such it is compliant with the dispositions of the GDPR.

III. DIFFERENTIATOR OF CAREKEEPER COMPARED TO THE STATE OF THE ART

Recent surveys on informal care coordination (e.g. [15]) distinguish among care apps and software platforms. Available care apps (e.g. Jointly, Birdie, CareLineLive, Carely, TCARE) have been designed to support families to better coordinate caregiving responsibilities, incorporating communication/messaging and note taking modules and simple calendars with reminders and appointments. However, our platform goes beyond simple calendars and messaging by exploiting AI models for risk detection, enabling AI scheduling and rescheduling, including all participants in the care workflow and handling emergencies.

On the other hand, software platforms that are used for care management and communication include Cera, Vida, PASSsystem, NurseBuddy, HomeTouch, Elder, Cariloop, Livpact etc. usually are used to match patients with carers, to communicate and share information. However, CareKeeper goes beyond simple message and information exchange,

whereas it does not try to match patients with carers, but to facilitate the needs of people already involved in the care process for specific patients.

Although the importance of informal care has been widely recognized as fundamental for the wellbeing and resilience of elders and patients with chronic conditions, there is still a limited availability of formal structures and monitoring tools. This lack results in duplication of efforts, increased costs and overall heterogeneous accessibility to care. Recent approaches so far are fragmented, focusing usually only on a specific disease, or on connecting patients with healthcare professionals, neglecting to some extent the role of informal caregivers. Our solution, based on a high-quality personal health record framework has been already tested in various diseases and domains. It exploits available patient data and existing AI models with user friendly apps to offer a holistic management and coordination of the informal care system.

IV. CONCLUSIONS

The CareKeeper proposed solution, builds a state-of-the-art personal health framework, with high technology readiness level, to enable informal care coordination. The CareKeeper risk assessment models can utilize different data and hence is easily incorporated to diverse use cases and diseases.

When coupled with relevant, quality certified training material, it has the potential to significantly improve patient monitoring support across all stages of the care pathway, while at the same time supporting research. CareKeeper can contribute to integrated pathways of care with better informed and prepared healthcare professionals, facilitating the transition to integrated care models across health and social services.

The AI and Big Data enabled application modules can further improve the value of current services, offering new and complementary functionalities, ensuring expansion and sustainability in the holistic management and coordination of the informal care system. The CareKeeper smart calendar and the CareKeeper communication and emergency modules facilitate the handling of daily tasks for all stakeholders involved including patients, caregivers and healthcare professionals. The CareKeeper services enable intelligent communication between patients, informal caregivers and professional carers, effectively managing their interconnections and exploiting advanced AI algorithms for supporting routine activities.

CareKeeper services offer customized, modular tools that have been developed through several R&D projects including BOUNCE (<https://www.bounce-project.eu>), iManageCancer (<http://www.imanagecancer.eu/>), MyHealthAvatar, Relief (<http://relief-chronicpain.eu>), STARS (<https://stars-pecp.eu/>), p-medicine (<http://p-medicine.eu>), REACTION and others. It has been extensively used and evaluated by patients, caregivers and healthcare professionals and is currently in the final stages for production level implementations.

CareKeeper services and tools can be applied in different domains and use cases. CareKeeper services can be incorporated in existing healthcare information platforms within healthcare facilities, regional health systems and other settings, offering a dynamic innovation to care management. The implementation of international interoperability standards, such as FHIR,

ensures seamless integration with existing or future interoperability enabled digital platforms contributing to the expansion and sustainability of technical and care services.

As next steps, the AI-enabled scheduling and rescheduling mechanism of the calendar will be fully implemented and more AI models will be also integrated with the validated models for detecting pre-frailty and frailty. Finally, although parts of the solution have already been evaluated with patients in several EU projects (most of the modules are currently being validated in the STARS-PCP H2020 project for perioperative stress reduction), the complete solution should also be evaluated.

ACKNOWLEDGMENT

Work presented in the paper is part of the Advanced Research Activities in Biomedical and Agro alimentary Technologies” (MIS 5002469), which is implemented under the “Action for the Strategic Development on the Research and Technological Sector”, funded by the Operational Program “Competitiveness, Entrepreneurship, and Innovation” (NSRF 2014–2020) and co-financed by Greece and the European Union (European Regional Development Fund)..

REFERENCES

- [1] European Commission, Informal Care In Europe, Exploring Formalization, Availability and Quality, Available Online: <https://ec.europa.eu/social/BlobServlet?docId=19681&langId=en>, visited May 2021.
- [2] J. Leniz, et al. “Electronic palliative care coordination systems (EPaCCS): a systematic review”. *BMJ supportive & palliative care*, 10(1), 68-78.
- [3] H. Kondylakis, et al. “Donor’s support tool: Enabling informed secondary use of patient’s biomaterial and personal data”. *IJMI*, 2017, 97, 282-292.
- [4] E. Verbakel, et al. “Informal care in Europe: findings from the European Social Survey (2014) special module on the social determinants of health”, *European Journal of Public Health*, 2017.
- [5] D. G. Katehakis, et al. “Personal Health ICT Systems to Support Integrated Care Solutions”. *FORTH-ICS/ TR-472*, Sep 2018. DOI: 10.13140/RG.2.2.28852.91524.
- [6] A Kouroubali et al. “iSupport: Building a Resilience Support Tool for Improving the Health Condition of the Patient During the Care Path”, *pHealth* 2019.
- [7] A. Kouroubali, et al. “Digital Health Tools for Perioperative Stress Reduction in Integrated Care”, *EJBI*, 2019, 16(2), 7-13.
- [8] D. G. Katehakis, et al. “An outbreak response tool to effectively support surveillance of suspect, probable and confirmed incidence cases while staying safe in COVID-19”, *BIBE* 2020, 432-437.
- [9] H. Kondylakis, et al., “Patient empowerment for cancer patients through a novel ICT infrastructure”. *J. Biomed. Informatics* 101: 103342, 2020.
- [10] M. Stratigi, H. Kondylakis, K. Stefanidis. “Fairness in group recommendations in the health domain”. *ICDE* 2017.
- [11] M. Stratigi, H. Kondylakis, K. Stefanidis. “Fairgreco: Fair group recommendations by exploiting personal health information”. *DEXA* 2018.
- [12] REACTION Consortium. D2.10 Final Validation Report of the Reaction Platform, 2014.
- [13] H. Kondylakis, D. Plexousakis, “Ontology evolution in data integration: Query rewriting to the rescue”. *ER* 2011.
- [14] N. Minadakis, et al. “X3ML Framework: An Effective Suite for Supporting Data Mappings”. *EMF-CRM@ TPD* 2015.
- [15] Digital Health & Care Institute, A Review of Digital Technology Solutions to Support Caregivers, March 2020, Available online: https://strathprints.strath.ac.uk/71767/1/Thomas_DHI_2020_A_review_of_digital_technology_solutions_to_support_caregivers.pdf, visited May 2021.