A step forward in supporting home care more effectively

Individually tailored in-home care consultancy utilizing machine learning

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ABSTRACT

Due to the ongoing demographic change, informal care is even more to be considered as main pillar in caring for the increasing number of care-dependent older people. However, informal caregivers do not feel sufficiently informed about suitable support measures and meeting their care tasks can pose a high burden on them. Therefore, in the nationally funded research project INGE an app was developed to implement quality-assured and outcome-oriented effective in-home care consultancy utilizing machine learning. Yet, data on home care are missing to build machine learning features. So, synthetic data generation was used in the INGE-project as compensation and improved later on by real data collected with the INGE app during in-home care consultancy visits. Outcomes of real data collection and the design of the INGE app will be presented in this paper.

CCS CONCEPTS

• **Human Computer Interaction**; • **Digital Health**; • **Machine learning**;

KEYWORDS

informal care, home care consultancy, home care assessment, app, visualisation

ACM Reference Format:
Henrike Gappa, Yehya Mohamad, Naguib Heiba, Daniel Zenz, Tassilo Mesenhöller, Alexia Zurkuhlen, Janine Pöpper, and Wolfgang Schmidt-Barzynski. 2022. A step forward in supporting home care more effectively: Individually tailored in-home care consultancy utilizing machine learning. In *10th International Conference on Software Development and Technologies for Enhancing Accessibility and Fighting Info-exclusion (DSAI 2022), August 31–September 02, 2022, Lisbon, Portugal.* ACM, New York, NY, USA, 6 pages. https://doi.org/10.1145/3563137.3563159

DSAI 2022, August 31–September 02, 2022, Lisbon, Portugal

ACM ISBN 978-1-4503-9807-7/22/08.
https://doi.org/10.1145/3563137.3563159

1 INTRODUCTION

The demographic change in European countries is known since long as well as the challenge to care for a rapidly growing number of older people in need of care. The vast majority of these older people is living at home and is cared for by informal caregivers also for long term. In Germany these are 80%[1], in other European countries the situation is similar[2], so informal care is to be seen as playing a pivotal role in the long-term care for older people. This high percentage fulfils the wish of many older people to remain living at home as long as possible. In some EU-countries informal care is incentivised by offering small care allowances or the possibility to reduce working hours due to the need for cost containment, staff shortage in the care sector etc. However, many informal caregivers feel overwhelmed by their care tasks which increases proportionally with the level of dependency of the care-dependent [1], but tend to seek help only in late stages of the care process rather than proactively which is also due to the complexity of finding the information relevant for their specific needs [2]. This situation contributes to the fact that informal caregivers suffer physically, mentally and emotionally when providing care to a family member [3].

To improve this situation, a care consultancy visit was installed in Germany that takes place at the homes of the care-dependents together with their informal caregivers. However, standards for this in-home care consultancy visit are very broad and the reimbursement puts strong time limitations on this visit (ca. 35 min.), so it is handled quite differently by service providers. It has to be conducted by a registered nurse and is mandatory for informal caregivers who receive care allowance. The objective of the visit is two-fold. Firstly, it shall examine whether the care-dependent is cared for well. Secondly, problems shall be identified that are due to the health status of the care-dependent and/or the informal caregiver's care burden and individually tailored support measures (interventions) are to suggest. Particularly the latter depends much on the individual knowledge of the nurse conducting the consultancy in regard to available aids and services. Next problem is that what was assessed by the nurse during a consulting visit as well as the suggested measures are hardly or often not at all documented,

[1]https://www.destatis.de/DE/Presse/Pressemitteilungen/2020/12/PD20_N083_224.html
[2]https://www.statista.com/statistics/1237241/elderly-care-recipients-and-potential-informal-recipients-in-europe/

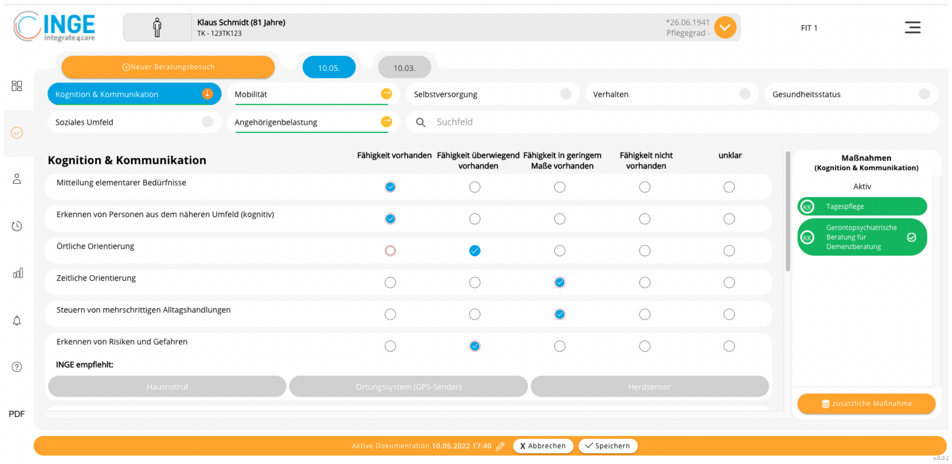

Figure 1: assessment items in the INGE app for category 'Kognition & Kommunikation' (cognition & communication)

which altogether poses an obstacle in achieving a continuous care planning.

The nationally funded research project INGE integrate4care (digitale INtegrierte GEsundheits- und Pflegeversorgung mit IT-gestütztem Pflegeberatungsbesuch nach §37.3 SGB XI/ Digital integrated health and home care with IT-supported in-home care consultancy in conformance to §37.3 social security statute book XI) aims to resolve the abovementioned problems by providing an app for nurses to assess a home care situation, document the results thereof and the suggested measures. Beyond this, the INGE-app utilizes machine learning to assist nurses in suggesting suitable support measures, if feasible, proactively and to analyse the status of a home care situation in comparison to similar care settings for risk assessment.

2 THE INGE APP

The INGE app was developed based on user requirements collected from nurses experienced with in-home care consultancy and assessment tools already validated and established in Germany for evaluating a home care situation. In Germany such assessments are performed by a physician on behalf of the German statuary health insurance with the goal to determine a person's individual level of care dependency. As a result, the care-dependent is assigned to a care level between 1 and 5. A higher number means a higher level of care dependency which influences the amount of care allowance an informal caregiver will receive and which support services this person is eligible for. The screening tool used for such purpose is the NBA (Neues Begutachtungsassessment zur Feststellung der Pflegebedürftigkeit/ New Assessment Tool for Determining the Level of Care Dependency) [4]. Since keeping the burden on informal caregivers within reasonable limits is considered quite crucial to maintain a home care situation, the INGE app assesses this issue more thoroughly than NBA by the BICS-D (Berliner Inventar zur Angehörigenbelastung-Demenz/Berlin Inventory of Caregiver Stress-Dementia). The BICS-D [5] is a validated screening tool to assess psychosocial impairments and the degree of burden arising from caregiving. Considering the objectives of in-home care consultancy and the time restrictions of this visit, a sub-set of the assessment items from the NBA and the BICS-D were selected by a group of nurses with extensive background in in-home care consultancy. As a result, 44 assessment items were taken over for the INGE app. Assessment items have to be rated by a 4- to 5-point Likert scale, rating whether a skill is present or not. In addition to the assessment items, personal and health information such as diagnoses, medication intake etc. are documented in the app. The assessment is described in more details in [6].

The INGE app is so far only available in German language. In Figure 1 a screenshot of the app's assessment part is presented. The assessment includes the following categories: 'Kognition & Kommunikation' (cognition & communication), 'Mobilität' (mobility), 'Selbstversorgung' (self-care), 'Verhalten' (behaviour), 'Gesundheitsstatus' (health status), 'Soziales Umfeld' (social environment) and 'Angehörigenbelastung' (burden on informal caregivers).

As mentioned above it is also an objective of the consulting visit to suggest appropriate measures. Therefore, the INGE app supports nurses in selecting such a measure by presenting 3 preselected possibly suitable measures from a catalogue of aids and services in case a preset cut-off value of a certain assessment item is reached (see Figure 1 in case a person's ability to realize risks and hazardous situations is diminishing or even lost (item: 'Erkennen von Risiken und Gefahren') installing an emergency call service (Hausnotruf), a GPS tracking system (Ortungssystem (GPS Sender)) and/or a stove guard (Herdsensor) could be suitable measures to prevent common hazards). These preselected measures were identified by a group of nurses with extensive experience in in-home care consultancy from a catalogue of about 200 measures recommended by the Remedies and Aid Registry for Care in Germany. This registry includes aids such as walkers, assistive technologies like stove guards and services to, e.g., support housekeeping or ease the care burden by day care. However, nurses are always free to select other measures from a catalogue compiled specifically for each category (see Figure 1 on the right side: 'zusätzliche Maßnahmen' (additional measures)). Nurses are always presented measures that have already been suggested and their status, e.g., 'Aktiv' (active) in case it has been implemented (see Figure 1 on the right side, e.g.,'Tagespflege' (day care)). Beyond this, the INGE app will consider patterns of assessment ratings to adjust the preselected measures according to what has been selected by nurses in similar situations with best outcome.

3 UTILIZING MACHINE LEARNING FOR IMPROVED HOME CARE CONSULTANCY

For data analytics and machine learning modelling, large repositories with high quality data sets are necessary. However, in the field of health care such data sets are often not available which is also the case for home care where hardly documentation takes place in case of informal care and little evidence-based knowledge is available about how home care situations progress over time, what are driving factors for improving, stabilizing or worsening of the situation [7]. As shown in the field of healthcare, machine learning (ML) bears also in this domain high potential to understand better risk factors of people in need of care and analyse the outcome of measures to improve, e.g., in-home care consultancy. Integrating home care domain knowledge into machine learning offers several advantages: (1) scalability of home care knowledge, (2) applying domain knowledge in supervised learning algorithms, (3) extending knowledge through continuous analysis of home care data and (4) cost effectiveness.

However, data to learn from are needed. In the following, the approach undertaken in the research project INGE will be described to install ML despite lacking real data about home care. The project aims to tackle this problem from two sides: a) building of a suitable data base for home care was initiated by hiring 4 care providers offering in-home care consultancy to conduct in total 300 consultancy visits with the INGE app, additionally the nursing service in the project used the INGE app for documentation of their consultancy visits striving for 500 visits at the end, b) utilizing synthetic data generation to setup the pipeline for predictive models in advance instead of waiting for real data and start training as well as testing ML-algorithms. Synthetic data generation is an acknowledged method used worldwide for the healthcare sector to compensate for lack of data when implementing ML models. More detailed information about the approach of synthetic data generation is available in [6]. However, this is not the only benefit of synthetic data generation. It can also be used to generate specific samples which are not available in the real data at that point. Thereby, it will help in making ML models more accurate and smarter. In INGE virtual cohorts were created using rules that are heuristic by translating them into transition matrices with transition probabilities, e.g., the probable further development of a care situation as documented by specific assessment item constellations with vs. without a measure. Transition matrices and outcomes were presented in iterative cycles to domain experts and then tuned until the generated synthetic data were satisfactory to the domain experts.

4 LEARNING FROM REAL DATA ABOUT HOME CARE

Once real data about home care situations were collected with the INGE app by service providers, analysis of data started, e.g., by investigating the home care situation in different care levels as well as evaluating the outcome of preselected measures to train ML-algorithms for improved suggestion of measures. First results of this analysis will be presented in the following.

4.1 Distribution of care-dependents and in-home care consultancy visits over care levels

As mentioned before, in order to generate more accurate synthetic data to train the INGE ML model, real data about home care are being collected by service providers. The real data are collected from care-dependents in all care levels; however, it is to mention that only few in-home care consulting visits were conducted with care-dependents in care level 1 and 5 (see Table 1). Since care-dependents assigned to care level 1 show only little care-dependency, informal caregivers of such care-dependents are often not seeking professional help and, therefore, care-dependents in this stage are often not diagnosed and thus do not have a care level. The opposite is the case for care-dependents in care level 5 who are highly reliant on care to the extent that these care-dependents need to be transferred to nursing homes where healthcare professionals take care of them. Due to the small sample of care-dependents in care level 1 and 5, these care levels were not included when analysing real data further. Table 1 also shows that at this point of time the number of follow-up visits (i.e. care-dependants have received a second or a third in-home care consultancy visit) is limited due to the recommended waiting time between consulting visits which is supposed to be 6 months for care level 1 and 2 and 3 months for care level 3, 4 and 5. Therefore, data available for analysis of follow-up visits is limited, but it is expected to get increased until the end of the project. So far, 180 care-dependents are distributed over the 5 different care levels as shown in Table 1.

4.2 Results from real home care data

Real data about a home care situation is systematically captured during the in-home care consultancy visit by assessing and documenting the situation with support of the INGE assessment (see

Table 1: care-dependent distribution over care levels and number of visits

Care level	Number of care-dependent	Number of visits	Number of follow-up visits
1	3	3	0
2	103	153	50
3	37	54	17
4	31	54	23
5	6	18	12

chapter 2). In order to understand better how home care situations differ across care levels and to find possible dependencies between different assessment categories within and across care levels, average scores of item ratings (value between 0 and 3 or 4 depending on the type of Likert scale) of each assessment category were calculated in percentages since the number of assessment items varies among assessment categories (see Figure 2). Results for care level 1 and care level 5 were excluded due to lack of sufficient number of consulting visits. Figure 2 shows results of the INGE assessment except for categories ‘personal data’ and ‘health information’ (e.g., diagnoses) which will be considered in the future as more consulting visits are documented.

In the following some findings that were derived from the data available so far and which we would like to highlight:

- In all care levels, category ’social environment’ (SU) shows the highest scores. In this category skills when interacting with known/unknown persons are assessed as well as topics affecting management of the social environment such as housekeeping and maintaining daily routines. The increase from care level 3 to 4 is comparatively high (+21.9%). However, it is to note that the relative increase from care level 2 (29.5%) to 4 (59%) with 100% is not much higher as the relative increase in other categories. In some categories, e.g., ‘cognition and communication’ this is even clearly beyond (see below).
- Categories ‘mobility’ (M) and ‘self-care’ (S) start with almost same scores, there are also similarities in the increase in scores, however, the gap in scores increases over care levels, so ‘self-care’ scores have increased by 222% from care level 2 to 4.
- In category ‘behaviour’ (V) average scores are comparatively low in all care levels, the increase is almost spread even among care levels (+2.8% from care level 2 to 3 and +2.7 from care level 3 to 4), nevertheless the relative increase between care level 2 and 4 is 89% which means it almost doubled as it is the case in other categories (care level 2: 6.2% vs. care level 4: 11.7%).
- The scores for category ‘cognition and communication’ (KK) shows with 345% the highest relative increase from care level 2 (5.6%) to care level 4 (24.9%).

In summary, findings above show that the loss of skills in regard to coping with the personal social environment seem to be most affected from care level 2 onwards. Abilities in categories ‘self-care’ and ‘cognition and communication’ seem to be much less concerned in care level 2, i.e., start with lower scores, however, scores increase higher over care levels, particularly in category ‘cognition and communication’ where the highest loss of independency is to observe from care level 2 to 4 (increase 345%). As Figure 2 shows, the loss of independency is increasing significantly when considering scores in care levels as benchmark (from 89% to 345%) which causes also an increasing burden on informal caregivers. Therefore, it is of utmost importance to support effectively informal caregivers in coping with their care tasks to maintain an acceptable care situation also long-term.

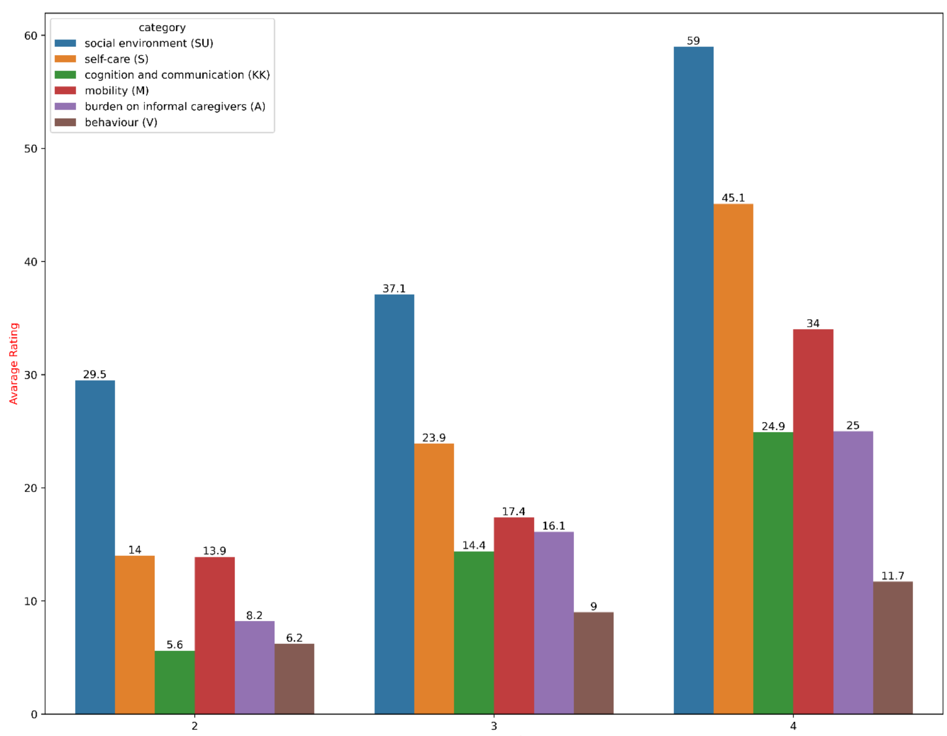

Figure 2: average scores of INGE assessment categories for care level 2, 3 and 4

4.3 Overview on suggested measures

As described earlier in chapter 2, the INGE app supports nurses in suggesting suitable measures by presenting 3 preselected measures from a catalogue of aids and services in case a preset cut-off value of a certain assessment item is reached. Analysis of collected data shows that certain measures have been widely suggested in different categories for different care-dependents (see Figure 3 showing the 10 most often selected measures). So far, the most suggested measure is "Entlastungsleistungen: Hilfeleistungen im Haushalt" (Assistance services: assistance with housekeeping) and it was suggested in total 58 times (see Figure 3).

The effectiveness of the measures was evaluated by comparing item ratings of the first nursing visit with ratings of follow-up visits. Not all care-dependents have yet follow-up visits which is an impediment for an accurate evaluation, but with the use of the available data, a short list of measures seem to have higher impact on how nurses rated the situation after these measures had been implemented. Higher impact in this context means item ratings show an improvement of skills, i.e., rating scores decreased in the follow-up visit. Nevertheless, when item ratings do not show a further decline in skills in the follow-up visits, i.e., ratings remain the same, this may also be considered as a good impact of the suggested measures, since maintaining a skill is in many cases already a success. Beyond this, it is to mention that in the assessment the status of skills known to affect a person's ability to live independently is assessed, so some measures will have a direct effect on this status, e.g., a walker allows a person to move around again independently, whereas others cannot directly improve a skill, but can have the effect to, e.g., ease the care situation.

Based on analyses of item ratings with the INGE assessment, aids 'Haltegriffe: fest montiert' (mounted grab handles) and 'Inkontinenzvorlage' (incontinence pads) achieved so far best outcomes. For two care-dependents measure 'mounted grab handles' led to lower scores in category 'self-care' (S) where this measure was suggested while one care-dependent improved in category 'behaviour' (V). Measure "Inkontinenzvorlage" (incontinence pad) was suggested to achieve improvement in category 'self-care' (S). Only one of three care-dependents whose scores lowered in the follow-up visits showed improved scores in category 'self-care' (S) though. For one care-dependent scores improved in category 'behaviour' (V) and for the other one in category 'burden on informal caregivers'. So, in these cases, the home care situation could be eased most likely. However, much more reliable data are needed to support such findings which will be the case once more follow-up visits are conducted with the INGE app.

Comparing care-dependents' ratings in initial visits with follow-up visits, then clustering care-dependents whose skills improved or remained the same can effectively support the pattern recognition process for identifying measures that bear the highest potential to have a positive impact on a home care situation. Such findings will be used in improving the quality of synthetic data generation. Generating accurate synthetic data used by the ML-component to suggest individually tailored measures with beneficial outcome in similar item constellations will support nurses in providing more effective measures.

5 CONCLUSION

Informal care is to consider as main pillar in the care of older people European-wide. Support of informal caregivers is still unsatisfying though and the burden poses risks for their health. Care consultancy is established in several EU countries to improve this situation, however, definite quality standards for consultancy are not installed yet. This is also due to limited knowledge about trends and risk factors of home care as well as evidence for counteracting measures. A main reason for this is missing data on home care and suitable means for analysis to derive such knowledge. As proposed in this paper the INGE app with its ML-component provides a solution to overcome this situation. It was designed for in-home care

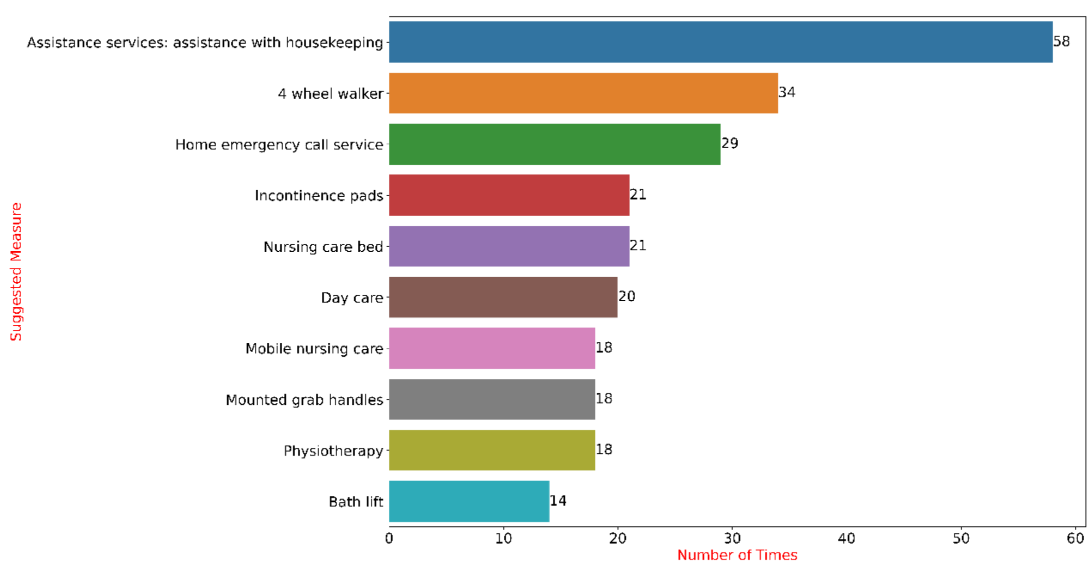

Figure 3: most suggested measures

consultancy in Germany, but it can be adapted to requirements of care sectors in other EU-countries. Until sufficient data are collected with the INGE app to base the ML-component on real data, a synthetic data generator was implemented to start training ML algorithms. Based on the framework built with synthetical data, the analysis of real data sets is currently conducted and findings are integrated, so results produced by the ML-component are gradually more and more based on real data and may in the future also provide authorities a knowledge base for anticipating future scenarios, e.g., how the aging population will progress over care levels and the service needs following thereof.

ACKNOWLEDGMENTS

This work was partially funded by the European Union from the European Regional Development Fund (EFRE) and the State of Rhineland-Westphalia (NRW), Germany (grant agreement number EFRE-0801905). The authors would like to acknowledge the support of the INGE consortium.

REFERENCES

[1] Nienke Lindt, Jantien van Berkel and Bon C. Mulder. 2020. Determinants of overburdening among informal carers: a systematic review. BMC Geriatrics, 20,304. https://doi.org/10.1186/s12877-020-01708-3

[2] Evi Willemse, Sybyl Anthierens, Maria I. Farfan-Portet, Oliver Schmitz, Jean Macq, Hilde Bastiaens, Tinne Dilles and Roy Remmen. 2016. Do informal caregivers for elderly in the community use support measures? A qualitative study in five European countries. BMC Health Serv Res, 16, 270. https://doi.org/10.1186/s12913-016-1487-2

[3] European Commission, Directorate- General for Employment, Social Affairs and Inclusion. 2021. Study on exploring the incidence and costs of informal long-term care in the EU. VC/2019/0227. European Commission Directorate- General for Employment, Social Affairs and Inclusion. https://data.europa.eu/doi/10.2767/06382

[4] Klaus Wingenfeld, Andreas Büscher and Barbara Gansweid. 2008. Gansweid, Das neue Begutachtungsassessment zur Feststellung von Pflegebedürftigkeit. Abschlussbericht zur Hauptphase 1, überarbeitete/korrigierte Fassung, Bielefeld/Münster.

[5] Anna Schlomann, Claudia Schacke, Bernhard Leipold and Susanne Zank. 2020. Berlin Inventory of Caregiver Stress - Dementia (BICS-D). The Gerontologist. https://doi.org/10.1093/geront/gnz195

[6] Yehya Mohamad, Alexander Gabber, Sonja Heidenblut, Daniel Zenz, Anam Siddiqi and Henrike Gappa. 2022. How to overcome lack of health record data and privacy obstacles in initial phases of medical data analysis projects. Computing and Informatics. Vol. 41 (1), 233-252. https://doi.org/10.31577/cai_2022_1_233

[7] World Health Organization. 2017. Integrated care for older people on community-level intervention to manage declines in intrinsic capacity. Geneva: World Health Organization. Licence: CC BY-NC-SA3.0 IGO. https://apps.who.int/iris/rest/bitstreams/1088824/retrieve