

Linked Care – A digital Revolution in Mobile Care and Support

Development and Implementation of a Digital Documentation System
for Interdisciplinary Information Transfer

Kathrin Mühlhauser

Department Health Sciences
FH Campus Wien
Vienna, Austria

e-mail: kathrin.muehlhauser@pmu.ac.at

Elisabeth Haslinger-Baumann

Competence Center for Applied Nursing Research
FH Campus Wien
Vienna, Austria

e-mail: elisabeth.haslinger-baumann@fh-campuswien.ac.at

Theresa Galanos

Competence Center for Applied Nursing Research
FH Campus Wien
Vienna, Austria

e-mail: theresa.galanos@fh-campuswien.ac.at

Franz Werner

Department Health Sciences
FH Campus Wien
Vienna, Austria

e-mail: franz.werner@fh-campuswien.ac.at

Doris Zeidler

Competence Center for Applied Nursing Research
FH Campus Wien
Vienna, Austria

e-mail: doris.zeidler@fh-campuswien.ac.at

Katharina Nopp

Department Health Sciences
FH Campus Wien
Vienna, Austria

e-mail: ka.nopp@protonmail.com

Abstract - Mobile care professionals are facing a great workload and a lack of information exchange with other health professionals. Documentation work is often done off-time due to minimal time resources. Information and communication technology support can bring improvements for home care and all stakeholders, but its full potential is not exhausted. This project, namely Linked Care, develops information technology systems that address practice-oriented challenges, increase digital data availability, and reduce the work-related burdens of health professionals as well as clients and their support systems. Experiences with existing IT-systems, including the current existing Austrian Electronic Health Record System, serve as a starting point to enable a continuous information supply in mobile care within the project. The solution will provide interdisciplinary support of relevant participants in the care process, offering a new type of responsive user interface. Linked Care investigates the end-users' needs and specifies the processes in workshops with local representatives and regional administrators. Therefore, the solution allows for the exchange and evaluation of care data via standardized interfaces throughout Austria while taking the socio-economic, regional, and national environments into account. The project will create a software portal that can be linked to existing systems. The project consortium parties ensure the development of the solution as a business model. The generated Care Summary creates new possibilities for data exchange within the health care sector. In conclusion, Linked Care is the digital solution, which needs to be implemented in mobile care and support as it enables a precise and rapid communication transfer.

Keywords - digital documentation; ICT; interdisciplinary communication; mobile health and care; digital healthcare.

I. INTRODUCTION

Nurses experience many burdens and challenges in their everyday work [1]. Documentation is often described as particularly stressful [2]. It is estimated that 30% of nurses' workload (working hours) is used for documentation. This time cannot be spent with clients, which in turn can lead to nurses finishing documentation work in their free time to have more available hours for direct client-based care [3]. The dramatically increasing number of people in need of care leads to an increase not only in the objectively measurable but also in the subjectively experienced care effort. As the complexity within the formal and informal care support network is increasing, the need for adequate client-related coordination between the involved parties is also growing. Continuous and detailed client documentation is the starting point of client related coordination and communication. However, the organization of client documentation in the care system is not only challenging in terms of effort, but it also shows deficiencies and complications regarding the information flow and exchange between the different formal and informal care giving/providing parties. Adequate documentation is indispensable for high-quality nursing and medical care, as well as interdisciplinary cooperation. Due to the dual financing system of medical care, nursing care and

homecare, the resulting responsibilities may be different in nature and “not necessarily conducive to the efficiency of the systems” [4]. Moreover, the lack of interdisciplinary exchange is closely related to financial and time constraints: only 60% of all mobile care service providers cooperate with professional groups outside their services [4]. On the one hand, the heterogeneity of the documentation and communication systems offered by different providers complicates the communication connection/link within the different mobile services/software solutions. On the other hand, the non-existence of an obligatory uniform solution forms a massive barrier to continuous information transfer. Sophisticated services, which are necessary to support recent technological innovations, have not been provided while creating data gaps in all areas of social welfare and health care. This causes discontinuance and translation problems within software solutions.

So far, the record validity was and is questionable due to existing language barriers between the carer’s first language and the available application languages. Comprehensive documentation is particularly important. For example, specific (target) groups were identified, that are not familiar with professional care within their households (e.g., ‘people with migration backgrounds’, ‘people with mental illnesses’). The reason is the lack of affordability in the presence of social disadvantage or the lack of information of particularly vulnerable groups, for whom care is mainly provided informally or within the family. This example points out the need for comprehensive documentation and communication that combines several information clusters. Therefore, it contributes to a subjectively facilitated situation and an objectively increased efficiency [4]. Beyond that, it also advocates the improvement of communication and interface management based on detailed surveys.

The aim of this project is to enable technology-based cooperation between clients as well as their support system and professional caregivers, nursing professionals, doctors, therapists, and pharmacies while using an efficient, secure and low-threshold digital tool, offering optimal information technology (IT) support.

This paper will provide insight into the Linked Care-project; starting with the ‘State of the Art’ in Section 2, followed by Section 3, ‘Method’, and finally describing the ‘Results’ as well as the ‘Conclusion and Further Works’ in Section 4 and 5.

II. STATE OF THE ART

Care network services, such as Linked Care wants to provide, currently exist worldwide, but they neither include all necessary participants and stakeholders (e.g., ‘medical care providers’, ‘pharmacies’, ‘care organizations’) nor do they function end-to-end on a digital level. Once integrated into one organization, other necessary services such as visiting services, home services and nursing care have to be organized by the employees [5]. That is their greatest detriment, which the Linked Care-solution wants to eradicate.

Most health care professionals in Austria currently work with the digital documentation system Mobile Case and Care

(Mocca) [6] and programs such as Gesellschaft für Software, Entwicklung und Datentechnik mbH (GSD Software®) [7] and Das Pflegeplanungs- und Dokumentationssystem mit ENP® (RECOM®-GriPS) [8], which are linked to one another via interfaces. Among the health care organizations involved in the Linked Care-project, documentation is still being practiced in analogue form while, in some cases, programs such as Microsoft Excel and Word are included. The use of dual documentation systems (simultaneous use of two systems by one organization) is currently also ubiquitous. This often results in double documentation, which leads to increased workload.

In the European Union (EU) and the United States of America (USA), there have been some digital developments in this field. Siemens eHealth Solutions [9] has created an electronic health network that brings together clients, care teams and medical doctors to exchange relevant data. This system was designed for the clinical setting and not for the homecare sector. Furthermore, it does not include clients involved relatives/support system or therapists. In the USA, the My HealtheVet portal [10] is available for Veterans by Veterans Health Administration (VHA) to renew prescriptions, organize doctor's appointments, contact health care teams, and retrieve information.

Online Care is a US-platform for clients and healthcare providers that is oriented towards GPS (or postcode) entries and enables corresponding connections. In Europe, cross-border healthcare data flow is already established, especially in the “eHealth Digital Service Infrastructure” [11]. Patient Summaries, ePrescriptions and eDispensation, are currently being rolled out. The Austrian Electronic Health Record System (ELGA, an acronym of Elektronische Gesundheitsakte) uses the same IT and technology standards, to create a feasible connection. In addition to numerous other initiatives, the EU is also striving for an “EU Health Data Space” to make available data more accessible for practical use within the healthcare system.

In consideration of all these innovative denouements the creative minds behind the project will pick out the best and combine them into the solution. At the end of development Linked Care will be a software portal that can be linked to existing systems (e.g., ‘ELGA’) with “one click”.

III. METHOD

The research project started in April 2021 and will last until 2025. The project includes five end-user partners (‘Akademie für Altersforschung am Haus der Barmherzigkeit’, ‘Johanniter Österreich Ausbildung und Forschung gem. GmbH’, ‘Wiener Rotes Kreuz- Rettungs-, Krankentransport-, Pflege- und Betreuungsgesellschaft m.b.H.’, ‘Volkshilfe Gesundheits- und Soziale Dienste GmbH’, and ‘Volkshilfe Wien gemeinnützige Betriebs-GmbH’), five technology partners (‘CareCenter Software GmbH’, ‘Loidl-Consulting & IT Services GmbH’, ‘Compugroup Medical CGM’, ‘Österreichische Apotheker-Verlagsgesellschaft m.b.H.’, and ‘Steszgal Informationstechnologie GmbH’), as well as three scientific partners (‘Fachhochschule Technikum Wien’, ‘Universität Wien’, and ‘Fachhochschule Campus Wien - Verein zur

Förderung des Fachhochschul-, Entwicklungs- und Forschungszentrums im Süden Wiens', whereby one partner is accountable for the information privacy protection mechanisms.

All required technical functionalities of the product will be identified and described by the team of developers and the potential end-users, while implementing the user-centered design approach [12], which is already currently running. To achieve these goals, Linked Care will allow for the exchange and evaluation of care data (e.g., 'nursing', 'care', and 'therapy') via standardized interfaces, such as Integrating the Healthcare Enterprise (IHE), Health Level 7 (HL7), and Fast Healthcare Interoperability Resources (FHIR) based throughout Austria.

A mixed-method approach, supported by profound literature research, is used to identify, and approach the target groups in question as well as implement the appropriate methods for the various target groups and settings. Within the first five months of the project, focus group interviews, one-on-one interviews, research diaries, and documentary analysis are conducted. These methods have been chosen to get an encompassing insight into the needs of the end-user. The use of a participatory approach [13] enables the involvement of people and groups that are difficult to reach (e.g., '24-hour care but also very vulnerable people'). All research methods are applied low threshold and in a culturally sensitive manner. The generated data is processed using a qualitative content analysis [14].

Additional stakeholders from the regional and national environment are involved to find solutions for specific challenges. Over the course of the project, goal-oriented, cross-disciplinary, and cross-role networks of individuals and organizations will be created. Sustaining and continuing these networks after the end of the project, represents one of the long-term project goals. Experts define acceptance factors in all development steps, which are validated several times during the project in an iterative manner and therefore, influence the development process directly.

Ethical concerns take a very important part in the development of the digital communication system. Therefore, ethical reflections are being carried out in the areas of care, self-determination, security, justice, privacy, participation, and self-image. For example, in terms of justice, it is ensured that everyone has equal access to the digital documentation, and that especially vulnerable groups such as low educational classes are not excluded. Security is discussed particularly in terms of IT security, but also in terms of the privacy of data.

IV. RESULTS

In total 43 one-on-one interviews, as well as five focus group interviews including 30 participations, were carried out in the summer of 2021 with people/experts from the fields of health, business and politics who represent the healthcare providers. Additionally, various digital and paper forms of nursing documentation are currently being analyzed.

The results of the project Linked Care contribute to the expansion and further development of innovative methods in

data collection and participatory product development. New knowledge tools are going to be developed, which will be available for further research issues in the field of care and support after the end of the project.

Currently, during the project, data gaps and new (data) information regarding the various stakeholders in the care sector are identified and collected. On the one hand, this data refers to the situation and needs of people in care as well as professional caregivers in the informal or formal sector. On the other hand, this data refers to the communicative interaction between the care and the medical sector. Thus, it provides a valuable basis for the development of new projects in both, the nursing, and the care sector. Furthermore, the newly developed data sets (indicators) will enable previously not used possibilities for data exchange in the care sector and for the first time allow for a standardized data exchange between general medicine practices and pharmacies as well as therapists and other stakeholders without digital data discontinuity. The comprehensive involvement of different service providers in the development of the product offers a solid foundation for the adoption of the product and ensures a high-quality exchange of relevant information. The job satisfaction of those working in the health sector may increase due to reduced documentation effort(s), duplications, and losses of information – leaving more time for the care of the clients themselves.

A. Healthcare Providers – Trends and Opinions

The results of the one-on-one interviews as well as the focus group interviews are currently being analyzed and evaluated, whereby first trends can be recorded.

1) *Important interfaces:* The clients' needs should be in focus and all health care professionals and providers engaged in the caring process of the client should intercommunicate, including doctors, nursing assistants, hospice, palliative care, etc. (depending on the intensity of care). Communication (also) allows for an exchange of information – the lack thereof can create insecurity and fear, which can result in further work-related errors. It is of utmost importance that health-related information is transparent and accessible to all parties involved. Therefore, it is essential that duplicate documentation is avoided to reduce time and cost resources and minimize the risk of errors. In order to guarantee a transparent information transfer and high-quality client medical treatment and care hospitals, regional health insurance funds, and pension insurance institutions (and many more) are important interfaces, and their staff members are hold on to share a client's documents and clinical documentation among each other

2) *Opportunities and risks of digitalization in healthcare:* All interviewed health professionals describe a very segmented documentation in the mobile nursing and care setting. None of the health professional groups mentioned (such as nurses, doctors, therapists) has

standardized access to the documentation of the other professional groups, even though they work with the same clients. This results in a large expenditure of time and resources for the collection of relevant information due to the non-access to digital documentation.

Another main finding of the survey is that clients are currently not involved in health documentation. This leads to dependencies and a great loss of information. A considerable challenge is therefore to involve the clients to strengthen their autonomy. Maintaining self-determination is an essential factor in health care, as the clients interviewed repeatedly emphasized. The documentation must be designed in such a way that the clients can influence it, for example by gaining access to the system and being able to grant permissions.

a) Firstly: Healthcare providers support the expansion of digitized information flows in the extramural area, but scepticism is omnipresent (regarding its success). Therefore, Austria (Linked Care) can learn from other countries, in terms of digital media/tools and documentation systems (e.g., ‘teleconsultation’, ‘video documentation’).

b) Secondly: A database needs to be connected to the Linked Care-solution, allowing clients to search for reliable information.

c) Thirdly: A digital tool should be added to ensure access to caring relatives and all parties involved. Also, a stored algorithm could be helpful – e.g., ‘when a blood glucose meter is needed in client care, and complementary diet advice is required’.

d) Moreover: Enhanced multidisciplinary access to healthcare data can be very helpful in successful therapeutic decisions and planning, further scientific research. On top of this, data protection and confidentiality are important aspects when it comes to healthcare

3) Further aspects and possible solutions: All interviewed parties describe the relevance of a patient-related documentation, which has to be available for all technical devices, even in offline mode – documentation should not be specific to occupational groups. Community nurses are an important interface in home care. The interviewed parties clarify that this professional group should be responsible for the communication between various healthcare professionals. The analysis of the interviews also display that at this point in time there is hardly any systematic terminology stored, which doesn’t allow for a presentation of nursing interventions comparably OR for effective and efficient comparison of nursing interventions.

Regarding the usability, the user interface should be clear, transparent, and not too complex in use, especially an intuitive usability of the digital system would be important. The language barrier of healthcare professionals poses a challenge – the Linked Care-solution should integrate a translation program and/or a digital dictionary.

B. Healthcare Professionals – Opinion Poll and Survey of Interests

In one-on-one and focus group interviews health professionals were asked about their opinion on the existing documentation system. They described prospects and their wishes regarding an optimal, interdisciplinary documentation system. The analysis is currently in progress. Early results show that healthcare professionals think that an interdisciplinary documentation system should include the following points:

- The digital system should integrate the planning and anamnesis, allow medical doctors to sign drug sheets and prescriptions digitally, enable physiotherapists and occupational therapists to document in the digital system, and all necessary parties involved to have access to this documentation.
- In addition, the digital documentation should be easy understandable and accessible for clients and caring relatives. Furthermore, health-related information should be automatically adopted when a client/patient is transferred from one to another organization. Above of this, risk surveys should be included in the digital program

C. Clients and their Relatives

The inclusion of affected clients and their relatives/support system, ensures the consideration of their needs and requirements in the (ongoing) product development process. This increases the quality of care considerably in two regards: Firstly, the improvement of care and nursing on a somatic level is addressed and secondly, the consistent participation of clients and their social environment also increases the quality of care according to the World Health Organization (WHO) comprehensive concept of health: Since physical as well as mental and social factors are equally included in the documentation process and clients themselves can play a decisive role during the process, they experience themselves as individuals with the power to act, who can influence their environment and living conditions. Having the power to act represents a central resource for subjective well-being according to the salutogenic approach [15].

The analysis of the one-on-one interviews with this target group is currently ongoing. At present, it can be said that each individual needs a different form of nursing, care and therapy. This should also be considered when it comes to healthcare and should be included in the nursing- and care process. Communication and a continuous exchange of information between the parties involved is particularly important – otherwise, the quality of nursing, care and therapy would suffer greatly.

D. Integrability into ELGA

The interoperability between the project solution and general practitioners’ software, pharmacies, and mobile services, is novel. The link to ELGA is seminal because it is the mainly used electronic health record system in Austria. The elaboration and application of indicators in the form of a care summary is an essential part of the content-related work

and is only possible in a meaningful way by bringing different areas closer together. The increase in knowledge is possible due to the cooperation of mobile services, economy, scientific partners, and those affected.

V. CONCLUSION AND FUTURE WORKS

The Linked Care-project is innovative. For the first time, the broad use of information and communication technology (ICT) and the strong networking of different organizations and stakeholders will make the assessment of practical benefits regarding intended functionalities for the mobile care services and relevant support system possible. In turn, this will also allow for an assessment of a user-need-based design of user interfaces. The user-centered design approach, which is applied in the whole research process enables this plan.

The mentioned background literature as well as the focus group and one-on-one interviews show first significant results. These results provide a solid basis for the ongoing research within the next four years.

ACKNOWLEDGEMENT

This research is sponsored by the Austrian research promotion agency (FFG) under grant number 884194. Project partners are: Akademie für Altersforschung am Haus der Barmherzigkeit, Johanniter Österreich Ausbildung und Forschung gem. GmbH, Wiener Rotes Kreuz- Rettung-, Krankentransport-, Pflege- und Betreuungsgesellschaft m.b.H., Volkshilfe Gesundheits- und Soziale Dienste GmbH (GSD GmbH), Volkshilfe Wien gemeinnützige Betriebs-GmbH, CareCenter Software GmbH, Loidl-Consulting & IT Services GmbH, Compugroup Medical CGM, Österreichische Apotheker-Verlagsgesellschaft m.b.H, Steszgal Informationstechnologie GmbH, Fachhochschule Technikum Wien, Universität Wien.

REFERENCES

- [1] K. Muehlhauser, E. Haslinger-Baumann, T. Galanos, D. Zeidler, and F. Werner, "Linked Care - Information Transfer in Mobile Care and Support" [Conference presentation abstract]. eTELEMED 2021 The Thirteenth International Conference on eHealth, Telemedicine, and Social Medicine, Nice, France, July 2021. Available from: http://www.thinkmind.org/index.php?view=article&articleid=etelemed_2021_2_80_40109.
- [2] E. Haslinger-Baumann, A. Lilgenau, C. Binder, and K. Gugenberger: "Quality characteristics in 24-hour care from the perspective of those affected. Results of a pilot survey study in Austria". In *Pflege Die wissenschaftliche Pflegezeitschrift für Pflegeberufe*, 2019.
- [3] B. Mittermann: "Long-term care: Where new challenges meet an old system". *Arbeit&Wirtschaft*. Available from: <https://www.arbeit-wirtschaft.at/langzeitpflege-herausforderungen/>.
- [4] M. Firgo and U. Famira-Mühlberger: "Expansion of inpatient care in the federal states. Quantitative and qualitative effects of the use of public funds compared to mobile care". WIFO. Vienna. Available from: <http://www.wifo.ac.at/wwa/pubid/47447>, 2014.
- [5] Care Network. Available from: <https://www.carenetwork.org.uk/>.
- [6] Ilogs healthcare GmbH. Available from: <https://www.ilogs.care/mocca/>.
- [7] GSD Gesellschaft für Software, Entwicklung und Datentechnik mbH. Available from: <https://gsd-software.com>.
- [8] RECOM GmbH & Co. KG. Available from: <https://docplayer.org/33810484-Leitfaden-recom-grips-v-online.html>.
- [9] Siemens Healthcare Diagnostics GmbH. Available from: <https://www.siemens-healthineers.com/at/digital-health-solutions/digital-solutions-overview/patient-engagement-solutions/e-health-solutions>.
- [10] My HealtheVet. Available from: <https://www.myhealth.va.gov/mhv-portal-web/home>.
- [11] CEF Digital Connectong Europe. Available from: <https://ec.europa.eu/cefdigital/>.
- [12] L. Jung-Joo: "Against Method: The Portability of Method in Human-Centered Design", Doctoral Dissertation, Aalto University, School of Arts, Design and Architecture, Department of Design, Helsinki, 2012.
- [13] M. Wright, M. Block, and H. V. Unger: "Levels of Participation in Health Promotion: A Model for Assessing Participation". In: *Gesundheit Berlin (Hrsg.): Dokumentation 13. bundesweiter Kongress Armut und Gesundheit*, Berlin, 2007.
- [14] U. Kuckartz, "Qualitative Content Analysis. Methods, Practice, Computer Support" (4th edition). Weinheim: Beltz Juventa, 2018.
- [15] A. Antonovsky, "Unraveling the mystery of health: how people manage stress and stay well". San Francisco: Jossey-Bass, 1987.