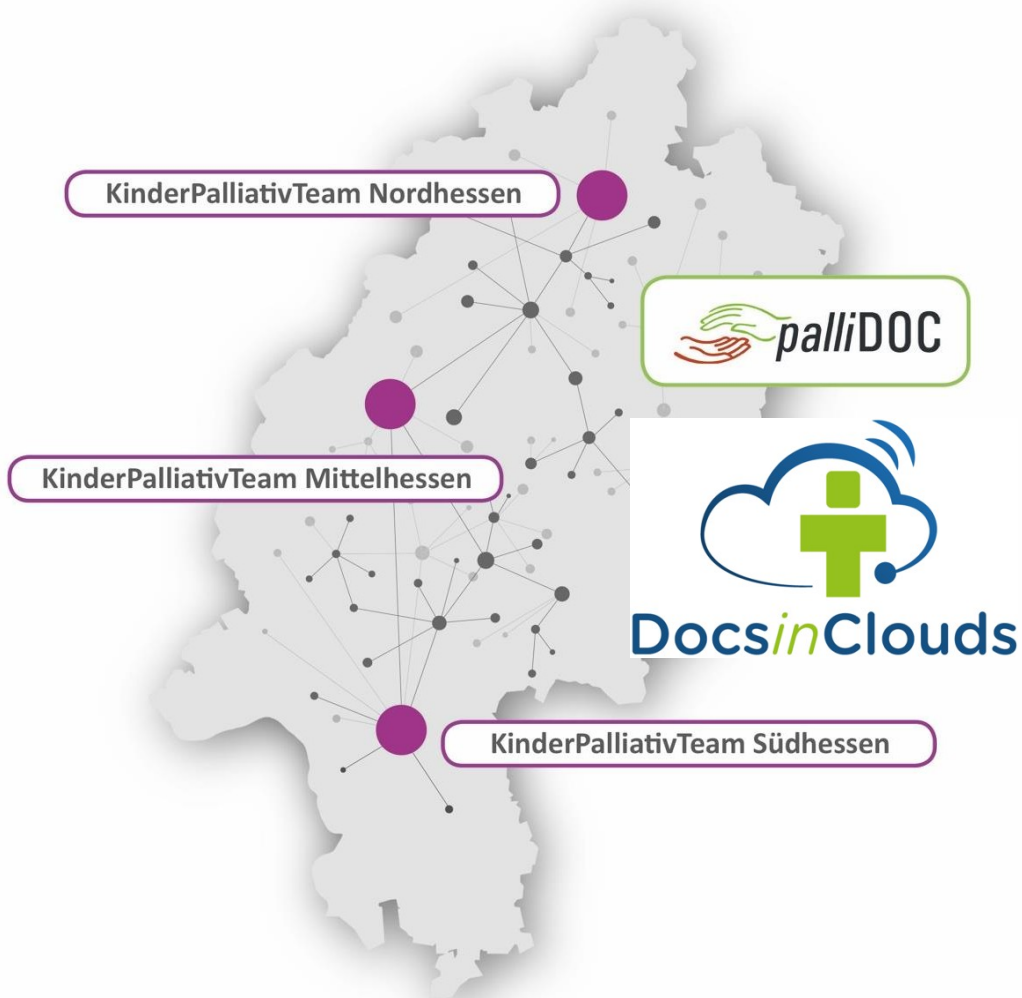




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FEASIBILITY STUDY OF A TELEMEDICINE APP FOR
SPECIALIZED PEDIATRIC PALLIATIVE HOMECARE
IN HESSEN, GERMANY

Telemedizin in der SAPV
von Kindern, Jugendlichen
und jungen Erwachsenen



The background: specialized pediatric palliative homecare care

Since 2007, there has been a legal entitlement (§37b SGB V) to specialized pediatric palliative homecare care (SPHC) for people with statutory health insurance in the Federal Republic of Germany. This relatively new form of care includes children, adolescents, and young adults (hereinafter referred to as "children") who suffer from an incurable, progressive or advanced disease with a limited life expectancy. These include children often suffer from severe neurological diseases, refractory tumor diseases or organ failure. Due to their special needs, specialized pediatric palliative homecare care (SPPHC) has been established nationwide. In Hesse, three SPPHC teams (KinderPalliativTeam Nord-, Mittel- und Südhessen, each based in Kassel, Gießen and Frankfurt) provide this care.

Adult specialized palliative homecare care (SPHC) is limited to caring for the last days and weeks of life, whereas SPPHC is often carried out over months to years, and SPPHC can be interrupted and resumed as needed. SPPHC thus includes end-of-life care as in adult SPHC, but also provides comprehensive day-to-day care for chronically seriously ill children. This includes medical and nursing care with regular telephone calls and visits and if necessary, emergency home visits during a 24/7 on-call service. Moreover, SPPHC offers psychosocial and spiritual support as well as coordination services to advise and network those involved in the outpatient care system to ensure adequate care for the patient and relief for the patient and family.

SPPHC is a helpful and cost-effective form of care for children and families. The challenge of SPPHC is to ensure a high quality and sufficient frequency of care over the spatial distance between patient home and SPPHC-Team office. Recurrent calls and home visits by physicians, nurses and psychologists sometimes do not suffice alone.

The project goals

This feasibility study aims to develop a telemedicine app for integration into SPPHC. Designed and tested in Hesse, after successful completion of the study the app will be available to all German speaking users and automatically synchronize with the popular patient management software PalliDoc®.

Initial scientific studies showed good efficiency and cost-effectiveness is possible for telemedicine interventions. Due to the complex requirements for the app regarding usability, comprehensive telemedical service spectrum, compliance with the German General Data Protection Regulation, and interfaces to current patient documentation systems, such an app is neither currently commercially available nor will it be in the foreseeable future.

By adding a telemedical app to SPPHC, we expect a relevant improvement in the quality and efficiency of care as well as an optimization of collaboration in the outpatient care system. However, it must be ensured that the use of telemedicine in SPPHC does not lead to a deterioration in the care of the patients and families concerned. The app is not developed to supersede in person delivery of SPPHC but to second it. Within the framework of this pilot study, we intend to develop algorithms for the integration of the app into SPPHC to ensure good care.

The project schedule

The 3-year feasibility study started in October 2021. First steps include a needs assessment of the families and three SPPHC teams in Hesse. Here, the unmet needs under SPPHC and between episodes of SPPHC and thus possible requirements for an additional app are to be assessed. Subsequently, the app is to be designed and programmed. Families and the SPPHC teams are actively involved in the sense of a “co-design”.

Upon completion of the app towards the end of 2022, a 16-month field trial and observational study is to start. Across Hesse, all three SPPHC teams will enroll patients in the trial. This will include quantitative surveys (acceptance, efficiency, effectiveness, usability) as well as qualitative surveys (acceptance, influence of telemedicine on trust and relationships between SPPHC staff and patients and their families). At the same time, the app will be continuously optimized and subsequently adapted to other operating systems so that the app fulfils "bring your own device" and works on the most commonly used devices (cell phones, tablet computers, desktop PCs from various manufacturers). Finally, the scientific project evaluation and publication will take place. In the following, an open telemedical consultation hour will be set up for patients and families interested in SPPHC.

The telemedical app in detail

Already in advance, three use cases for the app emerged as necessary functions:

1.) Video telephony: Anytime, immediate contact with the SPPHC team by patients and / or families with live audio-visual communication. In the event of medical crises, but also for planned follow up, this modality may possibly supplement SPPHC. In addition, it is also possible to integrate data from medical devices from the family (telemetric auscultation, transmission of vital parameters).

Moreover, by transmitting the family's stream to several terminals, multiple members of the SPPHC team and / or other involved health care professionals and institutions such as physicians with other subspecialties (e.g., neuropsychiatrists), pediatric hospice care services,

therapists can join the telemedicine consultation.

2.) Data transmission: The app enables the family to use their devices to submit photos, videos, sound recordings as well as files to the SPPHC and vice versa while assuring protection of data privacy.

3.) Elective telemedicine consultation: To facilitate early integration of palliative care we reach out to patients and families who are not yet receiving SPPHC but are legally entitled to it. The consultation does not render nursing or medical advice but solely informs about locally available SPPHC services.

Further functions are expected to be added after the needs assessment of families and SPPHC teams. Currently, a download area with information material for families and their network, a function for families to edit questionnaires, and the possibility for families to access the electronic patient file are emerging as further functions of the app.

The project environment

The consortium partners Kleine Riesen Nordhessen e.V., StatConsult Gesellschaft für klinische und Versorgungsforschung mbH, and Docs in Clouds TeleCare GmbH, together with the two cooperating KinderPalliativTeams Mittelhessen and Südhessen and the Institute for Psychology Theory and Methodology of Counseling at the University of Kassel, as well as the Fachverband SAPV Hessen e.V., provide the necessary prerequisites for the implementation of this pilot project: ongoing SPPHC, an identical online-based patient documentation system and the corresponding scientific and technical expertise.