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Implementation and Evaluation of a Mobile App to Support Communication in Paediatric Palliative Home Care: Results of a Multicentre Observational Pilot Study

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Abstract

Background:

Paediatric Palliative Home Care (PPHC) enables children, adolescents, and young adults with life-limiting conditions and a high symptom burden to remain at home. However, long travel times and 24/7 crisis availability present challenges to care delivery. Telehealth may improve both quality and efficiency of care. We developed the PalliDoc Mobile App for patients and caregivers using a co-design approach to support PPHC. The App provides features including video consultations, secure data transfer, and electronic patient-reported outcome measures.

Methods:

This single-arm multicentre observational pilot study was conducted between July 2023 and September 2024 in Hesse, Germany. The main inclusion criterion was the expectation that care would benefit from the intervention. Evaluation was guided by the RE-AIM framework, assessing reach, effectiveness, adoption, implementation, and maintenance. Data were collected via questionnaires and analysis of team information systems, using Excel 365 and R software.

Results:

Three PPHC teams continuously recruited 63 patients aged 3 weeks to 31 years over an 11-month period. The RE-AIM framework indicated that the App reached the target population (reach), was perceived as useful in healthcare (effectiveness), and was used by 18.8–52.4% of eligible patients receiving care (adoption). Six of seven asynchronous features were actively used in more than two-thirds of cases, and synchronous video consultations were used by 62% of families (implementation). At one-year follow-up, the App continued to be actively used by participating teams (maintenance). Families reported good usability, low burden, and no concerns regarding data privacy.

Conclusions:

The PalliDoc Mobile App appears to be a sustainable and beneficial addition to PPHC. Patients and caregivers reported perceived health-related usefulness and low burden. Asynchronous communication features were frequently used and integrated into routine care, whereas synchronous video consultations showed no measurable impact on PPHC delivery.

Registration

The study was registered the 13.01.2023 in the German Clinical Trials Register under DRKS00030546.

Introduction

Paediatric palliative home care (PPHC) enables children, adolescents, and young adults (hereinafter referred to as “children”) with life-limiting illnesses and a high symptom burden to be cared for in their home environment [1]. Specialised PPHC teams, comprising doctors, nurses and psychosocial professionals, ensure the provision of specialised outpatient palliative care for the children concerned. In the study region of Hesse, Germany, paediatric palliative home care is provided by three specialist teams based in Frankfurt, Giessen, and Kassel. The Hesse care model includes weekly home visit, telephone contacts as well as a 24/7 on-call and emergency response service in the event of a crisis [2]. PPHC improves the quality of life of the children affected [3], relieves the burden on family carers [4] and reduces the need to visit intensive care facilities [5;6]. At the same time, this presents challenges for PPHC teams. In routine care in Hesse, there has so far been no timely, data-protection-compliant method for the asynchronous exchange of information, such as updated medication plans, documents, photographs, or videos [7]. Furthermore, in crisis situations where no PPHC team is present on site, there is currently no means of conducting a rapid synchronous acute assessment remotely [7]. In such cases, an on-site assessment requires a travel time of up to 90 minutes each way [7].

Telehealth encompasses the umbrella terms Telemedicine and TeleCare and best describes the multidisciplinary delivery of palliative care [8]. Telehealth, such as the use of mobile apps, can provide support in synchronous and asynchronous communication [9] and thus contribute to better quality and effectiveness of care, and consequently to the quality of life of those affected. Consequently, telehealth is increasingly finding its way into various outpatient care structures as well as palliative care. However, there are currently few suitable apps available that meet the specific requirements of PPHC and do not focus on individual disease groups or patients with cancer [10;11]. Consequently, there remains a lack of appropriate solutions in many countries, including Germany [12].

As part of the pilot study evaluating a telehealth app for specialised paediatric palliative home care in Hesse, Germany (TelPa_kids), a needs assessment was conducted among the three PPHC teams in Hesse to identify requirements for the use of telehealth in PPHC [7]. Building on these findings, the PalliDoc Mobile App for patients and carers (hereafter referred to as ‘the App’) was developed, and its use is evaluated in the present study. We evaluated use of the App using the RE-AIM framework (Reach, Effectiveness, Adoption, Implementation, and Maintenance) [13;14]. This framework aims to “improve the sustainable adoption and implementation of effective, generalizable, evidence-based interventions“ and was used to assess the potential of the App and its features for various care settings and contexts [15].

Methods

In reporting the study, we have followed the CONSORT guidelines [16].

Study design

The pilot study was a single-arm trial. The aim of the study was to introduce the PalliDoc Mobile App in the state of Hesse, to further develop it in line with needs, and to evaluate it. This enabled us to gain initial findings to be gathered regarding the reach, effectiveness, acceptance, implementation, and maintenance of telehealth use in PPHC. All three PPHC teams operating in Hesse (Sites 1–3) participated in the study. The evaluation is based on an analysis of the collected care data, the German Telehealth Usability and Perceived Usefulness Short Questionnaire (G-TUUSQ) [17;18], which assesses usability and perceived usefulness in healthcare, and selected items from the modular Telemedicine Quality of Life Measure (Tele-QoL) [19; 20], which assess patients' burden associated with telehealth as well as their concerns regarding data processing and surveillance.

Participants and intervention

Patient enrolment was conducted by the PPHC team responsible for the patient's care, including the process of obtaining informed consent. Patients were eligible for inclusion if they (1) received care from one of the three participating PPHC teams, (2) were deemed by consensus of the responsible PPHC team to be likely to benefit from the App, and (3) had provided informed consent, either personally or through their legal guardians. Accordingly, the exclusion criterion, in addition to a lack of consent, is that the respective PPHC team expects the intervention to have neutral or negative effects on care. During the study period, a total of 186 patients were cared for, of whom 63 families were offered participation in the study.

Upon participation, the PalliDoc Mobile App was made available to the patient and/or the family and linked to the PPHC team's electronic patient record in the PalliDoc patient management programme. Each family had access only to their own data. The App offered eight distinct features (see Fig. 1). Asynchronous communication features included: 1) Participation in study questionnaires; 2) Viewing a calendar of scheduled appointments with the PPHC team; 3) Viewing the medication plan; 4) Viewing education / information material; 5) Data upload to the PPHC team (documents, photos, videos); 6) Viewing their own shared electronic PalliDoc patient file, i.e. stored documents such as doctors' letters and laboratory results and 7) Entering Electronic Patient Reported Outcomes (ePRO) regarding symptom severity. The only synchronous feature was (8) Participation in video consultations.

Outcomes and measurements

For the pre-analytical definition of the study measures, we followed the recommendations of the RE-AIM framework (Reach, Effectiveness, Acceptance, Implementation, Maintenance) [15]. We defined these as follows prior to conducting the study: **Reach**: Ratio of recruitment to consent and the sociodemographic characteristics of those treated compared to a comparison sample from a representative study [1]. **Effectiveness**: Perceived health-related usefulness from the families' perspective. **Adoption**: Description of the PPHC teams and the respective recruited patients. **Implementation**: Percentages of recruited families who use specific App features as well as absolute number of feature uses. Necessary

adjustments during the course of the study and their effect, effort, and costs. **Maintenance**: Percentage of families who enrolled but withdrew from the study. The number of teams that continue to use the patient App after the study has ended. Number of new Apps issued after the end of the study during the 12-month follow-up period.

The quantitative assessment of the study outcomes was conducted using routine care data. Sociodemographic information was collected via a dedicated questionnaire. Effectiveness was assessed using the G-TUUSQ [17, 18], a shortened version of the TUQ [21]. This also assesses the App's usability, which complements the RE-AIM framework, as usability is a key determinant of successful app use [22–24]. Moreover, selected items from TeleQol were used to assess patients' burden associated with telehealth as well as their concerns regarding data processing and surveillance [20]. We selected four items from the long version A of the modular TeleQoL that appeared suitable to evaluate the App: Item 9–11 and Item 22–23. The sociodemographic questionnaire was distributed upon enrolment in the study. The G-TUSSQ and selected TeleQol items were made available to families via the App after they had participated in a video consultation for the first time. We selected the first video consultation as the triggering event, as this always took place with the PPHC teams and constituted a key component of the App. Care data for the entire study period were extracted. These comprised: 1.) Sociodemographic and clinical data; 2.) a log of the features used within the patient App.

Sample size

The potential study size was limited to the number of families cared for by the three PPHC teams during the observational period. A total of 186 patients were cared for during this period.

No randomisation or blinding was carried out.

Statistical methods

Descriptive statistics were performed using R (version 4.4.2;25] using the packages psych, dplyr, readxl, hms, and openxlsx [26–30]. To analyse the G-TUUSQ, we calculated descriptive statistics such as means, confidence intervals, and standard deviations. Where several members of a family completed the G-TUUSQ, we aggregated the values per family. Due to the small number of missing values, we opted for pairwise exclusion, i.e. individual missing values were ignored in the respective calculation. We analysed the App's log file using Microsoft Excel 365. Our focus here was on which App features were used for each App issued.

Results

Recruitment

The roll-out of the App and prospective observational study ran from 17July 2023, to 25 September 2024. The pilot study was completed as planned.

Baseline data

During the study period, the PPHC teams in Hesse treated a total of 186 patients. The three PPHC teams asked different proportions of the families they cared for to take part in the study. Some teams were very cautious regarding the expected benefits of using the App or feared negative effects (see the 'Adoption' section). All families approached agreed and took part in the study. In total, 63 patients (33.8%) out of the 186 patients receiving care were included in the study.

Table 2 presents the sociodemographic characteristics of the participating patients, using categories developed by Nolte-Buchholtz et al. to describe a German PPHC cohort [1]. Half of the patients were in the age group between one and nine years (50.8%). In the sample, 42.9% of the patients receiving care were female. Most patients were cared for predominantly at home (87.3%) and jointly by both parents (61.9%). 81.0% of patients exhibited impaired communication, meaning they were unable to communicate verbally in complete sentences. During the study period, 17 patients (27%) died.

Based on the RE-AIM framework, the results of our study are as follows:

Reach. All 63 families invited to participate in the study took part (100%). The sociodemographic characteristics and medical conditions are largely comparable with those of published German cohorts of the PPHC [1]. However, this study included fewer infants and more primary school-aged children, and the proportion of patients with solid tumours and cardiac conditions was lower (see Tables 1 and 2).

Table 1
Sociodemographic data of the patients

	Total sample (N = 63)	
	n	**%**
Age		
Over 18	7	11.1
10–18 years	18	28.6
1–9 years	32	50.8
2–11 months	4	6.4
0–1 month	2	3.2
Gender		
Male	36	57.1
Female	27	42.9
Impaired communication [a]	51	81.0
Migration background		
No migrant background	48	76.2
With an migrant background	15	23.8
Residence		
Mainly at home [b]	55	87.3
Mainly care facility	8	12.7
Care [c]		
Together	40	63.5
Separated, by mother [b]	10	15.9
Other (facility, care service)	10	15.9
Separated, by father	1	1.6
Siblings with palliative illnesses [a]		
No	59	93.7

Note: Disease categories according to Nolte-Buchholtz et al. [1], supplemented by ‘Hepatic’ and ‘Metabolic disorder’. n = absolute number of individuals, % = percentage of individuals relative to the total sample; [a] N = 62, [b] including a foster mother, [c] N = 61

	Total sample (N = 63)	
	n	**%**
Yes	3	4.8
Died during the period of application	17	27.0

Note: Disease categories according to Nolte-Buchholtz et al. [1], supplemented by 'Hepatic' and 'Metabolic disorder'. n = absolute number of individuals, % = percentage of individuals relative to the total sample; [a] N = 62, [b] including a foster mother, [c] N = 61

Table 2
Diagnoses warranting palliative care

	Total sample (N = 63)	
	n	**%**
Oncological diseases	*14*	*22.2*
Brain tumour	8	12.7
Solid tumour	5	7.9
Leukaemia	1	1.6
Non-oncological diseases	*49*	*77.8*
Neuromuscular disorder	29	46.0
Neurodegenerative disease	12	19.1
Chromosomal aberration	4	6.4
Cardiovascular disease	2	3.2
Hepatic	1	1.6
Metabolic disorder	1	1.6

Note: Disease categories according to Nolte-Buchholtz et al. [1], supplemented by 'Hepatic' and 'Metabolic disorder'. n = absolute number of individuals, % = percentage of individuals relative to the total sample.

Effectiveness. The families surveyed rated the perceived health-related usefulness as very high, with a mean of 6.22 (SD = 1.12; 95% CI = 5.62–6.81, N = 16) on a 7-point scale. Table 3 contains the individual items of the scale used.

Table 3
Perceived health-related usefulness of the App

The app improves my access to healthcare services.	**M (SD)**	**95% CI**
	5.96 (1.69)	**5.06; 6.86**
The app provides for my healthcare needs.	5.9 (1.42)	5.14; 6.65
I would use the app again.	6.79 (0.54)	6.50; 7.08

Note: To assess perceived usefulness in health care, three items from the G-TUUSQ [17; 18], a short form of the Telehealth Usability Questionnaire [21], were used. Ratings on a 7-point Likert scale: 1 = strongly disagree to 7 = strongly agree; N = 16 patients

Adoption. During the study period, each of the three PPHC teams in Hesse had between 10 and 20 staff members. The teams cared for between 10 and 35 patients at any given time. One doctor and one nurse were each responsible for implementing the project within their team.

During the study period, each team continuously recruited families to take part in the study. Patient were included following a consensual, positive decision by the respective team regarding the expected positive benefits of the App for the family in question. This amounted to 14 (36.8%) of 38 patients cared for by Team 1, 16 (18.8%) of 85 patients cared for by Team 2, and 33 (52.4%) of 63 patients cared for by Team 3. The adoption rates of the teams thus ranged between 18.8% and 52.4%. In total, 63 (33.8%) out of 186 patients were offered the opportunity to participate in the study.

Implementation. The App was rolled out on 31 study tablets. The devices were distributed proportionally among the respective PPHC teams. During the course of the study, it became apparent that questionnaires and ePROs were not being completed, and that the tablets were often discharged when a video consultation was required, rendering them unusable. As the families did not appear to be using the tablets regularly, the team of authors decided to switch to a ‘bring your own device’ (BYD) approach prematurely - after just 4 months rather than 12 months - following the start of the Hesse-wide field trial, so that patients’ own devices could be used for the App.

The use of the App’s individual features were logged. Multiple App accounts could be assigned per patient in care. In some cases, only the patient or a single carer had access; in others, every carer and the patient themselves; a total of 108 App accesses were granted. In the following analysis, app accesses were aggregated into a single unit per patient receiving care (e.g. including family members) in order to provide a more realistic representation of usage patterns for each app feature (see Fig. 2). Overall, it was found that asynchronous features were mostly used by over two third of the families except “access patient record”. The medication plan (95.2% of families) was most frequently used. The App’s sole synchronous feature, video consultation, was used by 88.9% of families. However, these logs do not necessarily reflect a video-based exchange with the PPHC team but merely indicate that the relevant button has been clicked, as we documented a total of 129 video consultations (62% of families; data not shown).

The cost of project management and software development for the two principal investigators (PIs) was approximately €110,000. The cost of software development amounted to approximately €430,000.

The time spent on implementing the App by the two PIs totalled 30 hours per week over 1 ½ years; staff amounted to approximately €100,000. The project staff members in the teams did not receive any expense allowance for their participation in the project. The cost of the tablets was approximately €15,000.

Maintenance. During the study, none of the 63 patients withdrew from the study (completion rate 100%). All three teams (100%) continued to use the App with some of their patients after the study concluded; it was incorporated into standard care. During the 12-month follow-up period, a further 49 App accounts were provided.

Additional analyses

App usability

The families surveyed rated the App's usability as very high, with a mean score of 6.01 (SD = 0.69; 95% CI = 5.64–6.37, N = 14–16) on a 7-point scale. Table 4 contains the individual items of the scale used.

Table 4
Perceived usability of the App

It was simple to use the app.	**M (SD)**	**95% CI**
	6.18 (0.94)	**5.68; 6.68**
The way I interact with the app is pleasant.	5.97 (0.9)	5.49; 6.45
Whenever I made a mistake using the app, I could recover easily and quickly. [a]	5.9 (1.02)	5.31; 6.50

Note: To assess usability, three items from the TUUSQ [17;18], a short form of the Telehealth Usability Questionnaire [21], were used. Ratings on a 7-point Likert scale: 1 = strongly disagree – 7 = strongly agree; *N* = 16 patients; [a] N = 14 patients

Patient telemedicine burden and data processing & surveillance

Family ratings indicated that the App was not perceived as burdensome. In addition, concerns regarding unauthorised data access, data misuse, and data compromise were rated as low, suggesting that these issues were not perceived as problematic by family respondents (see Table 5).

Table 5
Patient telemedicine burden and data processing & surveillance

Patient Burden & Limitation	**M (SD)**	**95% CI**
	1.42 (0.97)	***1.09; 1.74***
Using telemedicine burdens me. [b]	1.56 (1.34)	1.10; 2.01
Using telemedicine overwhelms me. [b]	1.28 (0.78)	1.01;1.54
Data Processing & Surveillance	*2.06 (1.24)*	*1.64; 2.48*
I am concerned that unauthorized individuals might access my health data. [a]	2.4 (1.8)	1.78; 3.02
I am worried that my health data could be misused. [b]	2.19 (1.8)	1.58; 2.80
I am afraid that my privacy could be compromised through telemedical check-ups. [b]	1.58 (1)	1.25; 1.92

Note: To assess patient telemedicine burden and data processing & surveillance, items were selected from these two domains of the Tele-QoL [19;20] (patient burden & limitation: items 22–23; data processing & surveillance: items 9–11 of the Long Version A). Ratings on a 7-point Likert scale: 1 = strongly disagree – 7 = strongly agree; [a] N = 35, [b] N = 36

Harm/Adverse events

No harm or unintended effects resulting from the introduction of the App were reported during the teams' monthly study group meetings. However, a healthcare provider accidentally assigned a photo intended for wound documentation to the wrong patient, meaning that a family temporarily had access via the App to a photo of another patient's wound. However, as the misallocation was corrected swiftly on the same day, the family did not access the photo.

Discussion

The evaluation of the roll-out of the telehealth App for families affected by PPHC was conducted using the RE-AIM framework in order to assess the pilot project in a structured manner with regard sustainability, effectiveness, generalisability, and evidence base. In summary, the five domains of the RE-AIM framework showed that the App reached the target group (I. Reach), was perceived useful for healthcare (II. Effectiveness) and could be used for one-third of the patients receiving care (III. Adoption). Seven of the eight features were actively used in more than two-thirds of cases (IV. Implementation), and the app continued to be actively used by all teams during the year following the study period (V. Maintenance).

It is worth noting that the number of families included varied by team -ranging from one-fifth to half of the patients receiving care. From preliminary studies on the patient cohorts cared for by the participating teams and from regular joint quality circles, we know that these differ only marginally [31;32]. Accordingly, it seems implausible that these differences can be explained by patient factors. We suspect that the causes of the varying adoption rates in patient inclusion lie primarily within in the respective teams. For instance, staff shortages and turnover in two of the three teams during the study phase correlated negatively with adoption, which was also reflected in the reduced opportunity to participate in study group meetings.

All invited families took part in the study, did not withdraw during the course of the study, and perceived the App as very useful for healthcare. This points both to a good selection of families by the PPHC teams and to the quality of the App. However, the generalisability of these findings to all patients receiving PPHC is limited by the inclusion criterion of an ‘expected benefit for the family’, which may have introduced selection bias. Each team decided individually for which patients the App promised added value in care and therefore offered the App only to specific patients.

The frequent use of the mainly asynchronous App features reflects the tailoring of the App according to the project's initial needs assessment for the Hessian care region [7]. All App features were used in over two third of patients except the access to other documents from the PPHC team which was used by only about one third of families (34.9%). However, although video consultations were the App’s only synchronous communication feature and were accessed by 88.9% of families, only 119 video consultations were documented, involving 62% of families. Consequently, video consultations were among the less frequently used App features.

Despite being identified as a high priority in the needs assessment [7], ePROs were used less frequently than all other asynchronous communication features by families. Two points should be noted here. Firstly, during the field testing, the symptom assessment tool for the PPHC was still under development. The first version of the tool was evaluated as part of this study and is currently undergoing further development within our research group. Secondly, the App does not allow families to view the previously recorded symptom severity scores themselves. Both factors may have contributed to the infrequent use of ePRO.

In contrast, the medication plan was the most frequently used of all asynchronous features, reflecting the value of providing families with continuous access to up-to-date medication information. Its use also facilitated more accurate and timely management of medication plans by the PPHC teams. Furthermore, the medication plan was increasingly used to support communication with outpatient care services regarding medication administration. Accordingly, the medication plan was exported in 34.3% of App instances (data not shown).

App usability, data protection and the lack of burden

The App's usability was rated very positively overall. The sub-area receiving the most critical assessment was troubleshooting. This is consistent with the experiences of team members, who found that, particularly with video consultations, it was usually not possible to resolve failures quickly and easily (data not shown). We also consider it particularly important that the families did not feel this was a burden. Moreover, the protection of data was neither a major concern of the families.

Limitations

The varying proportion of patients included per team suggests a selection bias of varying degrees. The subjective leeway allowed by the inclusion criterion (expected positive benefit for care) may have exacerbated this effect.

The chosen inclusion criterion makes it difficult to draw conclusions about the benefit for the entire patient population, i.e. including those patients for whom the PPHC teams do not expect a positive benefit for care. The inclusion criterion was deliberately chosen to prevent overburdening patients and family members who are often already under significant strain. The response rate to the questionnaire survey was low. One obvious reason for this may be that the respondents face severe challenges and the survey was lost amidst the daily routine of care.

Generalizability

The pilot study was conducted in Germany, in the state of Hesse. Consequently, the App developed specifically for this purpose was tested as a supplement to the Hesse PPHC and its geographical and infrastructural conditions. The transferability of the results to other countries and healthcare systems requires further research.

Interpretation

The findings of this study suggest that, in particular, asynchronous App-based features tailored to the specific needs of families can complement PPHC without adversely affecting patient care. The evaluation results further support the perceived usefulness of the App in healthcare delivery. However, the impact on patient-relevant outcomes, such as quality of life, could not be assessed within the scope of this observational study. Moreover, demonstrating effects on such outcomes in future studies may prove challenging owing to the expected ceiling effects associated with PPHC [33].

Declarations

Ethics approval and consent to participate

The study was conducted in accordance with the Declaration of Helsinki and approved by the Institutional Ethics Committee of the Universities of Kassel (protocol code EK-Nr. 202213, 18 February, 2022) and Giessen (protocol code AZ 64/22, 20 May, 2022). Informed written consent was obtained from participants prior to participation.

Consent for publication

The participants’ consent to publication was obtained.

Availability of data and materials

The data presented in this study are available on request from the corresponding authors. The data is not publicly available due to privacy concerns. For further information on the TelPa_kids study, see: https://www.kleine-riesen-nordhessen.de/kinderpalliativteam/telemedizin (accessed on July 1, 2025).

Conflicts of interest

The authors declare that there are no financial or non-financial conflicts of interest. The PalliDoc Mobile app was developed by StatConsult, the distributor of the PalliDoc software and PalliDoc Mobile App, based on specifications defined by the research team. Development of the app was supported through funding from the public funding body listed below. StatConsult was not involved in the scientific evaluation of the project and had no influence on the analysis, interpretation, or reporting of the study findings.

The software used in the study was provided to the participating PPHC team members with direct patient contact by the vendor at a discounted rate. The discount was not subject to any conditions. No profit-sharing payments were made.

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Authors' contributions

The authors MD, HM, MN, TV & JZ contributed to conception and design of the study. MD, KS, SG, SK, CM, VV, TV & JZ conducted the study and data acquisition. MD, KS, RH & JZ analysed and interpreted the data. MD, KS, RH, VV & JZ drafted to manuscript; MD, KS, RH, SK, CM, HM, MN, VV, TV & JZ revised the manuscript. All authors approved the submitted version and agreed both to be personally accountable for the author's own contributions and to ensure that questions related to the accuracy or integrity of any part of the work, even ones in which the author was not personally involved, are appropriately investigated, resolved, and the resolution documented in the literature.

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Other Information

Registration

The study was registered the 13.01.2023 in the German Clinical Trials Register under DRKS00030546.

References

1. Nolte-Buchholtz S, Zernikow B, Wager J. Pediatric patients receiving specialized palliative home care according to German law: a prospective multicenter cohort study. Children (Basel). 2018;5(6):66. doi:10.3390/children5060066.
2. Engler J, Schütze D, Hach M, Ploeger C, Engler F, ELSAH-Gruppe, et al. Spezialisierte ambulante Palliativversorgung für Kinder, Jugendliche und ihre Familien – die besonderen Belange der Zielgruppe. Ergebnisse der ELSAH-Studie. Bundesgesundheitsbl. 2022;65:357-366. doi:10.1007/s00103-022-03500-7.
3. Marcus KL, Santos G, Ciapponi A, Comandé D, Bilodeau M, Wolfe J, Dussel V. Impact of specialized pediatric palliative care: a systematic review. J Pain Symptom Manage. 2020;59(2):339–364.e10. doi:10.1016/j.jpainsymman.2019.08.005.
4. Groh G, Feddersen B, Führer M, Borasio GD. Specialized home palliative care for adults and children: differences and similarities. J Palliat Med. 2014;17(7):803–10. doi:10.1089/jpm.2013.0581.
5. Berkmüller M, Gravou-Apostolatou C, Rascher W. Quality of pediatric palliative care crisis intervention – a retrospective survey study. Klin Padiatr. 2021;233(6):286–291. doi:10.1055/a-1589-5854.
6. Lysecki D, Chanchlani R, Gupta S, James Lee J, Rodrigues M, Thabane L, Wilson C, Zucchet D, Perez R. Reductions in regional end-of-life resource utilization following development of a specialist pediatric palliative care program. Oral presentation at: EAPC 2026; 2026 May 14; Prague, Czech Republic.
7. Zimmermann J, Heilmann ML, Fisch-Jessen M, Hauch H, Kruempelmann S, Moeller H, Nagel L, Nathrath M, Vaillant V, Voelker T, et al. Telehealth needs and concerns of stakeholders in pediatric palliative home care. Children (Basel). 2023;10(8):1315. doi:10.3390/children10081315.
8. Busse TS, Burner-Fritsch I, Deckers M, et al. Digitalisierung in der Palliativversorgung – Chancen und Herausforderungen: Bericht zum veröffentlichten Positionspapier der AG Digitalisierung. Zeitschrift für Palliativmedizin 2023;24:226–228. doi:10.1055/a-2123-6770.
9. Lundereng E, Nes A, Holmen H, Winger A, Thygesen H, Jøranson N, Borge C, Dajani O, Mariussen K, Steindal S. Health care professionals' experiences and perspectives on using telehealth for home-based palliative care: scoping review. J Med Internet Res. 2023;25:e43429. doi:10.2196/43429.
10. Steindal SA, Winger A, Riiser K, Bjørnerud E, Chen W, Holmen H. Health technologies and infrastructures for supporting home-based pediatric palliative care: scoping review. J Med Internet Res. 2025;27:e70687. doi: 10.2196/70687.

11. Tan Y, Liang X, Ming W, et al. A scoping review of digital technology applications in palliative care. *BMC Palliat Care*. 2024;23:290. doi:10.1186/s12904-024-01626-w.
12. Cruz S, Fernandes C, Magalhães B. A scoping review of mobile apps for use with palliative patients in the context of home care. Int J of Med Inform. 2023;177:105166. doi:/10.1016/j.ijmedinf.2023.105166.
13. Hancock S, Preston N, Jones H, Gadoud A. Telehealth in palliative care is being described but not evaluated: a systematic review. BMC Palliat Care. 2019;18:114. doi:10.1186/s12904-019-0495-5.
14. Glasgow RE, Vogt TM, Boles SM. Evaluating the public health impact of health promotion interventions: the RE-AIM framework. Am J Public Health. 1999;89(9):1322–7. doi:10.2105/ajph.89.9.1322.
15. RE_AIM. What is RE_AIM. https://re-aim.org/learn/what-is-re-aim/. Accessed 5 Jun 2026.
16. Eldridge SM, Chan CL, Campbell MJ, Bond CM, Hopewell S, Thabane L, Lancaster GA, PAFS consensus group. CONSORT 2010 statement: extension to randomized pilot and feasibility trials. BMJ. 2016;355:i5239. doi:10.1136/bmj.i5239.
17. Zimmermann J, Scharf F, Deckers MJ. G-TUQ: German version of the Telehealth Usability Questionnaire [procedural documentation, questionnaire for practitioners and patients, short version for patients (G-TUUSQ)]. In: Leibniz Institute for Psychology (ZPID), editor. Open Test Archive. Trier: ZPID; 2025. doi:10.23668/psycharchives.21343.
18. Zimmermann J, Morf H, Scharf F, Knitza J, Moeller H, Muehlensiepen F, Nathrath M, Orlemann T, Voelker T, Deckers M. German Version of the Telehealth Usability Questionnaire and derived short questionnaires for usability and perceived usefulness in health care assessment in telehealth and digital therapeutics: instrument validation study. JMIR Hum Factors. 2024;11:e57771. doi: 10.2196/57771.
19. Greffin K, Muehlan H, van den Berg N, Hoffmann W, Ritter O, Oeff M, Speerfork S, Schomerus G, Schmidt S. Correction to: Measuring context that matters: validation of the modular Tele-QoL patient-reported outcome and experience measure. Qual Life Res. 2024;33:1437–1441. doi:10.1007/s11136-023-03594-9.
20. Schmidt S, Muehlan H, Greffin K. Ergebnisbericht—Settingsensitive Konzeptualisierung und Erfassung der Lebensqualität in der telemedizinischen Versorgung. 2023. https://innovationsfonds.g-ba.de/downloads/beschluss-dokumente/299/2022-12_16_TELE-QOL_Ergebnisbericht.pdf. Accessed 5 Jun 2026.
21. Parmanto B, Lewis AN Jr, Graham KM, Bertolet MH. Development of the telehealth usability questionnaire (TUQ). Int J Telerehabil. 2016;8(1):3–10. doi:10.5195/ijt.2016.6196.
22. Venkatesh V, Thong JY, Xu X. Consumer acceptance and use of information technology: extending the unified theory of acceptance and use of technology. MIS Q. 2012;36(1):157–178. doi:10.2307/41410412.
23. Venkatesh V, Morris MG, Davis GB, Davis FD. User acceptance of information technology: toward a unified view. MIS Q. 2003;27(3):425–78. doi:10.2307/30036540.

24. Venkatesh V, Zhang X. Unified theory of acceptance and use of technology: US vs. China. J Glob Inf Technol Manag. 2010;13(1):5–27. doi:10.1080/1097198X.2010.10856507.
25. https://cran.r-project.org/doc/manuals/r-release/fullrefman.pdf R Core Team. R: A language and environment for statistical computing. 2025. https://cran.r-project.org/doc/manuals/r-release/fullrefman.pdf. Accessed 1 Juk 2026.
26. Revelle W. psych: Procedures for psychological, psychometric, and personality research. R package version 2.6.1. 2026. https://CRAN.R-project.org/package=psych. Accessed 5 Jan 2026.
27. Wickham H, François R, Henry L, Müller K, Vaughan D, Posit Software, PBC. dplyr: A grammar of data manipulation. R package version 1.2.0. 2026. Accessed 5 Jan 2026.
28. Wickham H, Bryan J. readxl: Read Excel files. R package version 1.4.5. 2025. https://CRAN.R-project.org/package=readxl Accessed 5 Jan 2026.
29. Müller K. hms: Pretty time of day. R package version 1.1.4. 2025. https://CRAN.R-project.org/package=hms. Accessed 5 Jan 2026.
30. Schauberger P, Walker A. openxlsx: Read, write, and edit xlsx files. R package version 4.2.8.1. 2025. https://CRAN.R-project.org/package=openxlsx. Accessed 5 Jan 2026.
31. Engler, J, Schütze, D, Hach, M et al. Spezialisierte ambulante Palliativversorgung für Kinder, Jugendliche und ihre Familien – die besonderen Belange der Zielgruppe. Ergebnisse der ELSAH-Studie. Bundesgesundheitsbl. 2022;65:357–366; doi:10.1007/s00103-022-03500-7.
32. Hach M, Seipp H, Haasenritter J, Kuss K, Engler J, Schuetze D, Becker D. Results report (in accordance with No. 14.1 ANBest-IF): evaluation of specialized outpatient palliative care (SAPV) using the example of Hesse https://innovationsfonds.g-ba.de/downloads/beschluss-dokumente/94/2021-08-20_ELSAH_Ergebnisbericht.pdf. Accessed 26 Feb 2026.
33. Boyden JY, Bogetz JF, Johnston EE, Thienprayoon R, Williams CSP, McNeil MJ, et al. Measuring Pediatric Palliative Care Quality: Challenges and Opportunities. J Pain Symptom Manage. 2023 May;65(5):e483-e495. doi:10.1016/j.jpainsymman.2023.01.021.

Figures

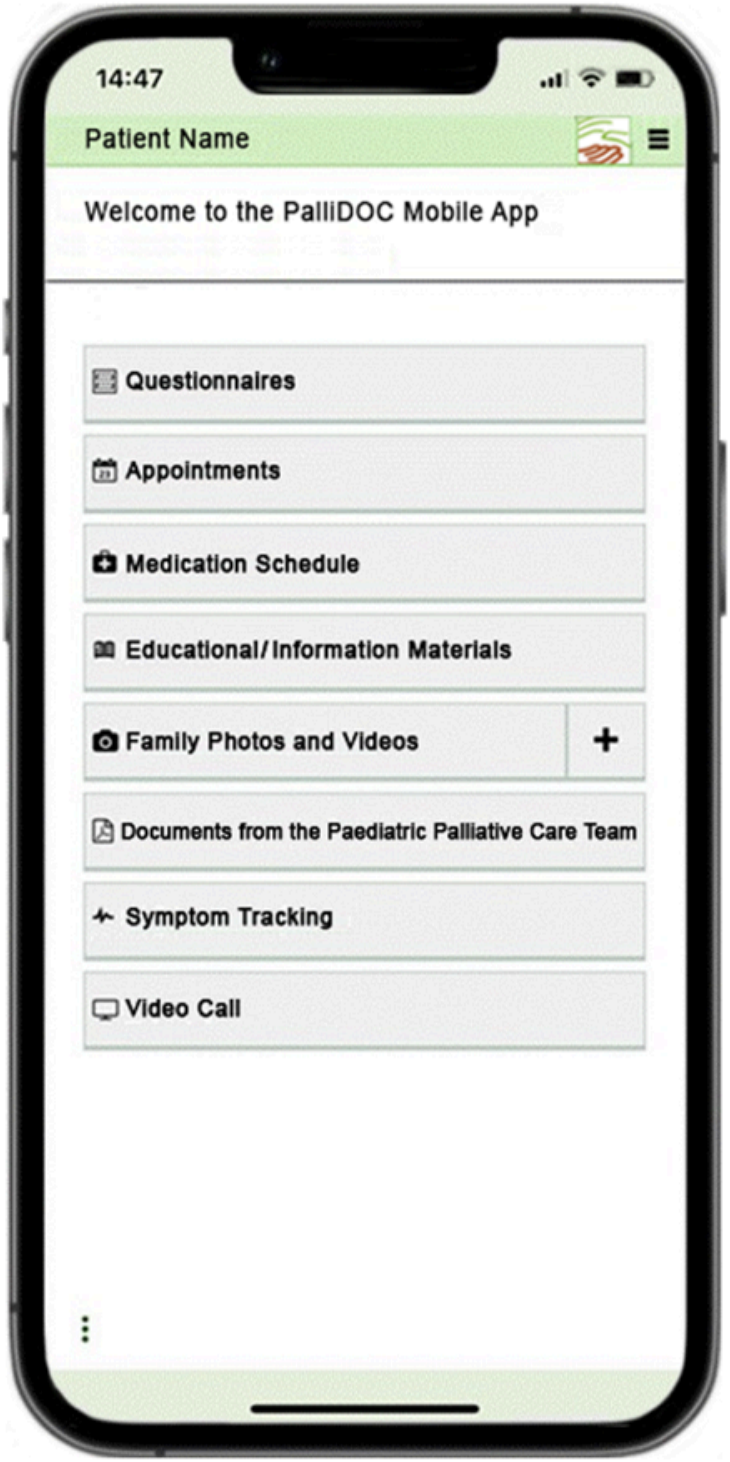


Figure 1

Home screen from the patient version of the PalliDoc Mobile App.

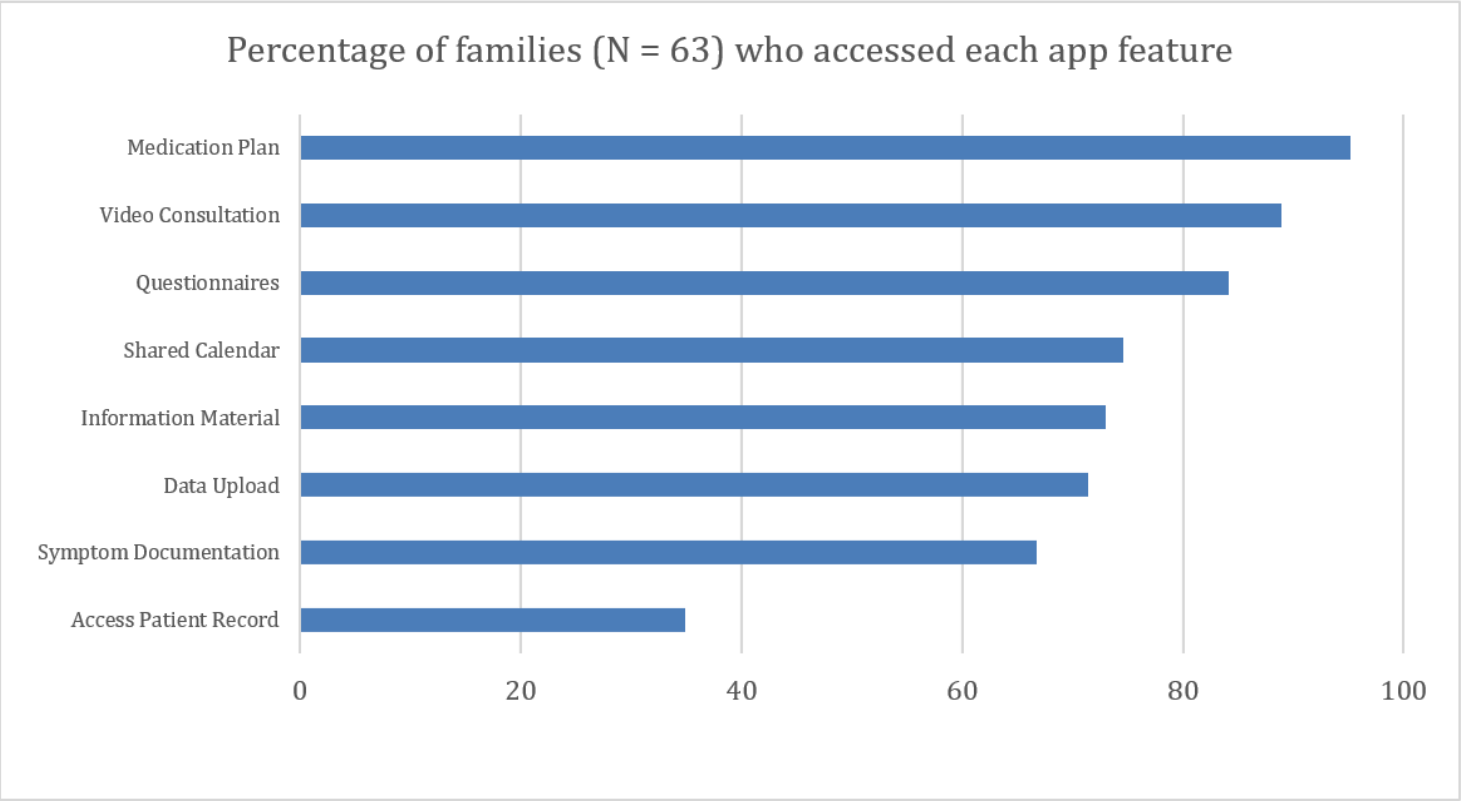


Figure 2

Percentage of families (N = 63) who accessed each app feature