



# Telemedically augmented palliative care

## Empowerment for patients with advanced cancer and their family caregivers

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### Summary

**Background** Studies have shown that initiating early palliative care of patients with end-stage cancer can improve their quality of life and decrease symptoms of depression. The challenge is to find an effective way to care for these patients while minimizing the burden on healthcare resources. Telemedicine can play a vital role in solving this problem.

**Methods** A user-friendly telemedical device enabling patients encountering medical problems to send a direct request to a palliative care team was developed. A controlled feasibility study was conducted by assigning 15 patients with advanced cancer and their family caregivers to receive either standard palliative care or telemedically augmented palliative care. The quality of life (QoL) was assessed using standardized validated questionnaires as well as frequency and duration of hospital admissions and user satisfaction. The primary goal of this study was to increase the QoL of patients and their family caregivers. The secondary goal of this study was to decrease the frequency and duration of hospital admissions.

**Results** This study showed a good feasibility despite the low overall willingness to participate in a relatively “technical” trial. The hospital anxiety and depression scale (HADS) was significantly lower in the intervention group, suggesting an improved quality of life. Although a decrease in the number of hospital admissions could not be shown, the user satisfaction was very good.

**Conclusion** Telemedicine could be a useful tool to enhance the general well-being of palliative oncology patients. Now that the feasibility of this approach has been confirmed, larger studies are needed to verify its positive impact on the QoL.

**Keywords** Supportive care · Teleoncology · Family caregivers · HADS · Quality of life · Advanced cancer

### Background

According to the World Health Organization (WHO) palliative care is the active total care of patients whose disease is not responsive to curative treatment [1]. The goal is the achievement of the best possible quality of life (QoL) for patients and their families. Control of pain, other symptoms and psychological, social and spiritual problems is paramount [1]. Palliative care in hospitals and hospices requires a multidisciplinary team, consisting of nurses and physicians with additional training and, if required, physiotherapists, social workers and psychologists.

In 2005, a total of 180 hospice and palliative care services existed in Austria, of which 131 were mobile services. In the year 2016, the number of services nearly tripled to 443, of which 218 were mobile [2]. These data are within the European average. Since the inpatient and mobile care merges, it is difficult to obtain an exact number of patients who are taken care of. The standard deviation age range of patients

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receiving palliative care is between 67 and 75 years old and more than three quarters suffer from cancer [2]. The increasing service numbers, particularly of mobile hospice teams, reflect the population's need for help. Therefore, upgrading and extending this particular sector is an important mission.

End of life care for many patients with advanced disease is provided by a family member who undertakes and/or coordinates the majority of care [2]. Unfortunately, the stress of providing care often results in experiencing elevated levels of emotional distress, resulting in a deteriorated QoL [3–6]. One of the main stress factors is the amount of care given, which severely affects the lifestyle of the family caregivers [7]. Fleming et al. [8] assessed the association between perceptions of healthcare quality and QoL for both patients and family caregivers. They showed that the presence of depression in family caregivers correlated with family caregivers being less satisfied with the quality of healthcare being given to the patients. Interestingly, they demonstrated that the patient's mental health and depression scores correlated with those of the family caregivers. These data suggest that terminally ill patients and their family caregivers share similar perceptions and evolve as a "unit of care". These findings are also supported by Northouse et al. [9]. When patients and family caregivers are treated simultaneously with psychoeducational interventions, skills training and therapeutic counselling, important synergies are achieved that contribute to the well-being of each person. Programs of care that are directed at patients alone are seldom sufficient to meet patients' needs, because a lot of the patient care depends on family caregivers. The authors performed a meta-analysis to analyze data obtained from 29 randomized clinical trials, published from 1983 to March 2009. The analysis showed that interventions (e.g. providing information regarding symptom management, skills training, therapeutic counselling) that are provided for the family caregivers of cancer patients had a significant positive effect on multiple outcomes, such as better QoL [9]. Interestingly, interventional effects for some outcomes were evident soon after the intervention. A study by Temel et al. [10], published in the *New England Journal of Medicine* in 2010, focused on the advantages and patient-related outcomes of initiating early palliative care for patients with advanced non-small cell lung cancer (NSCLC) as compared to patients who received standard palliative care. They reported an increase in QoL and decrease of depressive symptoms in the intervention group. Notably, they found an increase in median survival of approximately 2 months for those patients receiving early palliative care (11.6 months vs. 8.9 months,  $p=0.02$ ). As a conclusion, palliative care with intensive symptom management and psychosocial support should begin as early as possible in patients with NSCLC who have a high burden of disease together with high mortality.

Telemedicine describes the electronic delivery of medical data for diagnostics, treatment and medical education to the patient at home by the use of information and communication technologies. The main purpose of telemedicine is the improvement of patient care (improved diagnostics and treatment), combined with an increase in efficiency and cost-effectiveness of medical services [11, 12]. A term often used in the literature is teleoncology, which describes the application of telemedicine to oncology, including diagnostics (e.g. laboratory investigations, radiology and pathology), treatment (e.g. surgery, radiation oncology and medical oncology) and supportive care (rehabilitation and palliation). Therefore, the term teleoncology includes any telemedical application used to support cancer care, whereas telemedicine as an umbrella term describes any telemedically augmented intervention [13–15]. Teleoncology may have the potential to improve access to and quality of clinical cancer care. In order to investigate the effect of telemedical care on QoL in patients with advanced cancer and their family caregivers, a feasibility study was conducted.

## Methods

The primary aim of this project was to show that telemedically augmented palliative care may improve QoL of patients and family caregivers. The secondary aim was to see if telemedicine potentially decreases the number of hospital admissions.

The iPad Minis and Health Insurance Portability and Accountability Act (HIPAA) conform video call application "VSee" was used to link oncology patients and their family caregivers to the responsible physician at the palliative care unit at the department of internal medicine. The iPad was always kept close to the physician in charge, including nightshifts, thus enabling the patients to electronically ask for medical advice around the clock. There was no time schedule for getting in contact; the patients and their family caregivers could use the app whenever they felt the need for medical help. Video conferencing was chosen because it allows more personalized communication than telephone calls and might therefore improve the effectiveness and efficiency of communication. Visualization of patients also allows a (limited) physical assessment to be undertaken, which can assist with patient management and care. Additionally, an application database was established. The application was used to document the patient's vital signs (e.g. temperature, blood pressure, pulse and oxygen saturation) as well as ongoing treatment and some other parameters (e.g. pain, nutrition, body weight and a dairy function) and provided a graphic visualization of data. It was not only fed by the physician in charge but also by patients and family caregivers. Again, there was no time schedule for data entry but the study participants were encouraged to make up to

date information available to the physician in charge, facilitating decision-making in the case of emerging medical problems. If the medical request could not be solved by telemedicine, the patient was admitted to hospital.

Patients and family caregivers received a unique identification (ID) number. The collected medical data were stored in relation to the ID number, thus ensuring anonymity. Physicians already registered as medical users at the Medical University of Vienna, had to identify themselves with a username and password to access the database and the VSee app. Additionally, the physicians received detailed training for data security to ensure maximum safety precautions. By maintaining these specifications, the telemedical support was in accordance with the Austrian Data Protection Act.

To assess QoL and mood, the validated questionnaires quality of life in palliative cancer care patients QLQ-C15-PAL (QLQ), hospital anxiety and depression scale (HADS) and caregiver satisfaction with advanced cancer care (FAMCARE) were used [16, 17]. These questionnaires were filled in at two different points in time. All patients filled in HADS and QLQ-C15-PAL, whereas the family caregivers filled in HADS and FAMCARE. The first survey was performed at the beginning of this project (baseline), the second survey was conducted 10 weeks after baseline. Additionally, patients and family caregivers of the intervention group filled in a questionnaire regarding their satisfaction with the telemedical support. This questionnaire was self-created and included inquiries about usability (e.g. time spent for data entry), overall satisfaction (e.g. if the study participants would recommend the telemedical support or participate again) as well as perceived effect on QoL.

Between 2012 and 2016 a total of 15 oncological patients with advanced cancer were recruited at the Department of Internal Medicine and at the Department of Dermatology at the Medical University of Vienna/General Hospital of Vienna. Each patient was recruited with one family caregiver. Participation or non-participation had neither benefits nor disadvantages for patients' healthcare. Patients were consecutively assigned to two groups, a control group and an intervention group. Study participants of the intervention group received the telemedical support system (which they kept until death), whereas the other group received standard care.

Inclusion criteria were patients of any sex between 18 and 75 years old, patients with advanced cancer, patients with an Eastern Cooperative Oncology Group (ECOG) performance status of 0 or 1, as well as patients with an ECOG of 2 without cognitive impairment. To describe the results, an intention to treat analysis was performed. To evaluate if the mean QLQ scores were different between the patients in the intervention and control groups, a linear regression model was calculated with the QLQ score after 10 weeks as

a dependent variable and the baseline score as a covariate. The same was done for the FAMCARE questionnaire. Patients as well as caregivers answered the HADS questionnaire, so additionally the "unit of care" (patient plus respective caregiver) was specified as a random effect.

## Results

### Demographics

A total of 15 patients and their caregivers gave informed consent of which 8 were consecutively assigned to the control group. The mean age of all study participants (patients+caregivers) was 49.9 years in the control group and 47 years in the intervention group, 17 study participants were male and 13 female. Of the family caregivers 87% were the patient's spouse and 13% were the patient's children. The most common tumor entity was NSCLC ( $n=9$ ), followed by melanoma ( $n=4$ ) and pancreatic cancer ( $n=2$ ).

### Quality of life

The QoL was assessed at baseline and 10 weeks after baseline using validated questionnaires (HADS, QLQ-C15 and FAMCARE). Scores were calculated and analyzed for course and differences among the two study groups. There were no statistically significant differences in FAMCARE and QLQ-C15 scores between the control and the intervention group (Figs. 1 and 2; Tables 1–2); however, the course of the HADS score was significantly better in the intervention group ( $p=0.042$ , Fig. 3; Table 3).

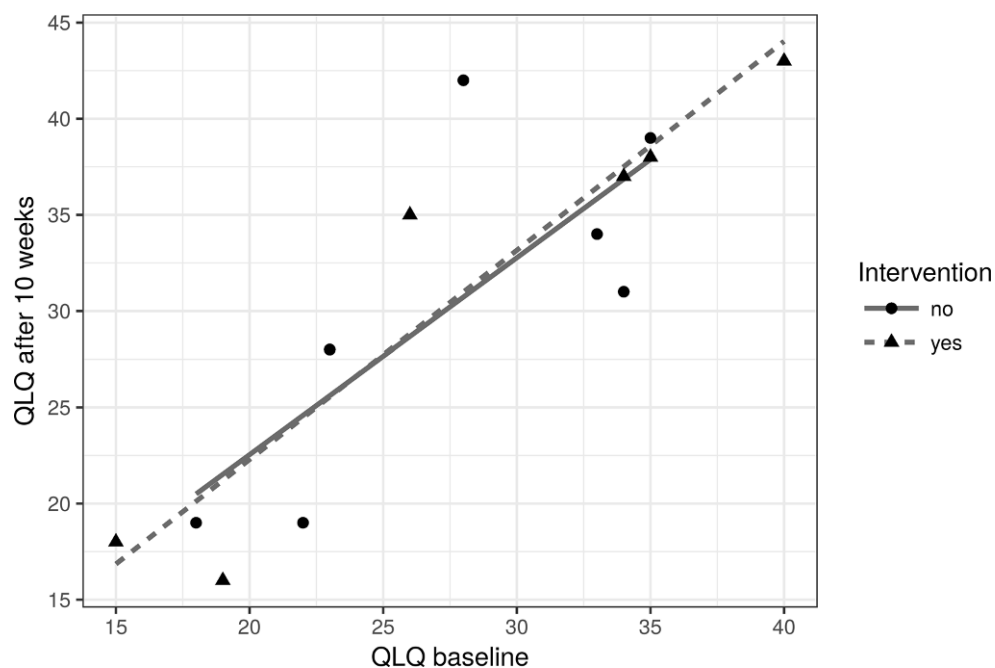
### Hospital admissions

There were 6 admissions in the control group versus 7 admissions in the intervention group; therefore, no statistically significant differences among the two study groups could be found.

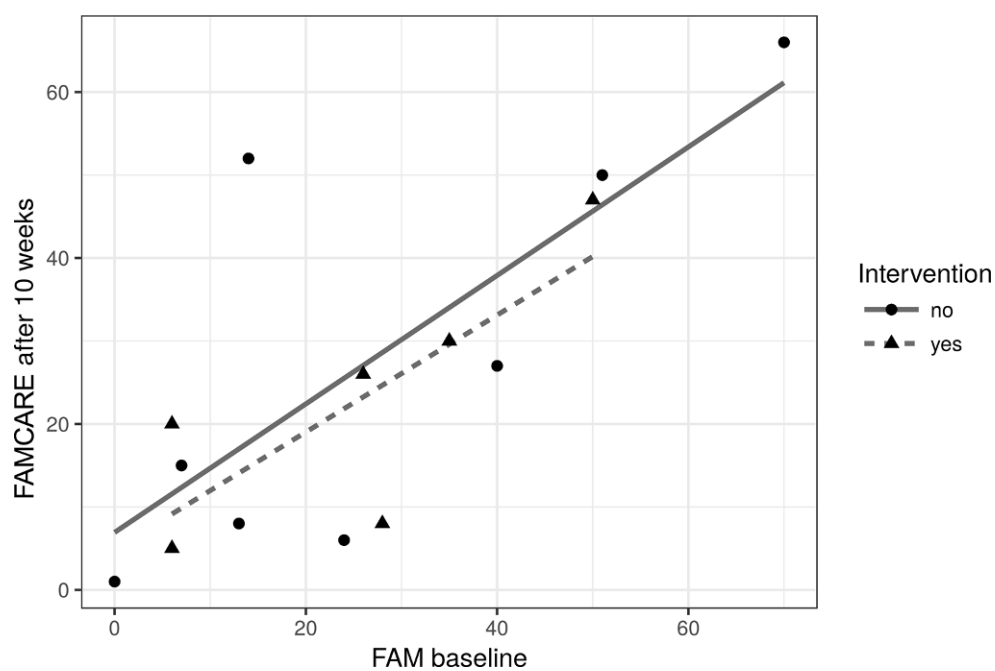
### Usability/perception

All of the study participants believed that telemedically augmented care will play an important role in the future and 86% would participate again in this trial or recommend it to other patients but 14% did not answer the question. By means of Austrian school grades (1–5; 1="very good", 2="good", 3="fair", 4="sufficient", 5="insufficient"), general usability (application, data entry) was rated "very good" or "good" by 64.3% of study participants, "sufficient" by 7.1% and 28.6% did not answer the question, 71% stated that data entry was easy and comprehensible (yes-no question), whereas 19% did not answer the question. Of the intervention group 50% stated that they did not feel that they spared themselves unnecessary hospital admission due to the telemedical

**Fig. 1** Graph showing a comparison of the Quality of life in palliative cancer care patients (QLQ) scores for the intervention and the control group. Slopes were calculated in a linear model



**Fig. 2** Graph showing a comparison of the Caregiver Satisfaction with Advanced Cancer Care (FAMCARE) scores for the intervention and the control group. Slopes were calculated in a linear model



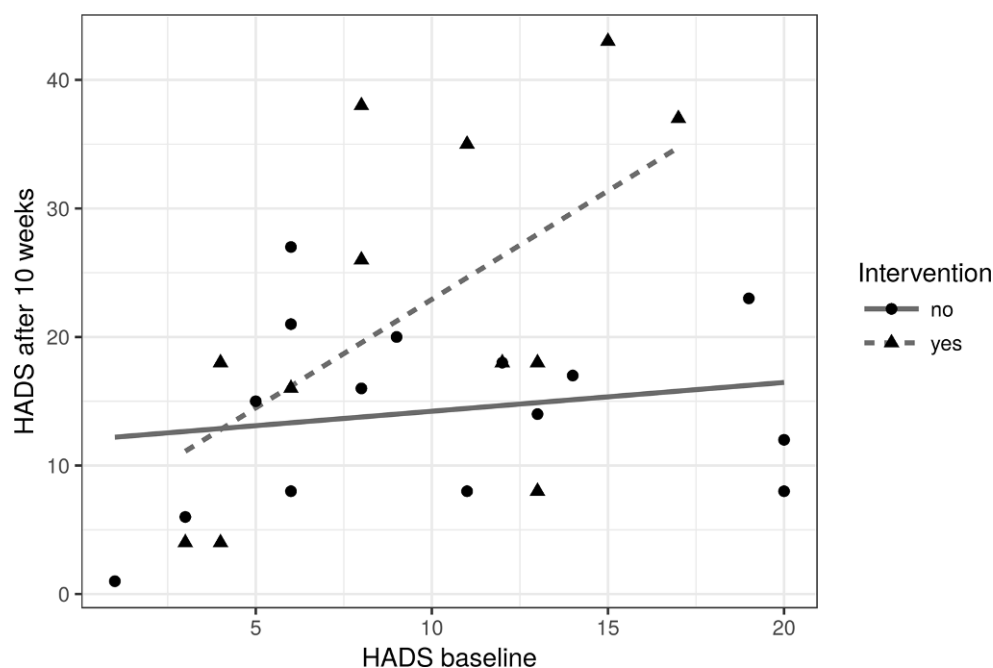
**Table 1** Linear regression analyses of Quality of life in palliative cancer care patients (QLQ) scores of patients receiving standard or telemedically augmented palliative care

	Estimate	Std. error	t-value	p-value
QLQ (baseline)	1.064	0.191	5.572	<0.001
Intervention	0.248	2.916	0.085	0.934
<i>QLQ, Std.</i>				

**Table 2** Linear regression analyses of Caregiver Satisfaction with Advanced Cancer Care (FAMCARE) scores of family caregivers in the intervention and control group

	Estimate	Std. error	t-value	p-value
FAMCARE (baseline)	0.756	0.194	3.894	0.003
Intervention	-3.788	7.826	-0.484	0.638
<i>FAMCARE, Std.</i>				

**Fig. 3** Graph showing a comparison of the Hospital Anxiety and Depression Scale (HADS) scores for the intervention and the control group. Slopes were calculated in a linear model



**Table 3** Linear mixed model analyses of Hospital Anxiety and Depression Scale (HADS) scores for patients and their family caregivers in the intervention and control group

	Estimate	Std. error	t-value	p-value
HADS (baseline)	0.686	0.362	1.893	0.07
Intervention	8.297	3.871	2.143	0.042
<i>HADS, Std.</i>				

support, whereas 21% stated the opposite and 29% abstained. Of the intervention group 57% felt they were “more” or “a bit more” supported by telemedical support, whereas 21% felt “equally” supported. No one felt “less supported”; the remaining 22% did not answer the question, 78.6% stated that they felt their overall quality of life was enhanced by the telemedical support, 7.1% stated no difference and no one felt their quality of life was worsened and 14.3% abstained.

#### Telemedical requests and consultations

A total of 37 telemedical requests were submitted of which 35 were successful, whereas 2 failed. Reasons for failure were technical problems (uncharged battery, logged off VSee app). Out of 37 requests 3 were emergencies, 11 requests dealt with subacute problems and the majority of requests [22] dealt with nonacute problems. Merely 9 out of 35 consultations were rated by the study participants (1–5 possible stars); the mean value was 4.9 stars, indicating a very high satisfaction.

#### Data entry

A total of 638 data entries were performed. Entry count varied between 1 and 265 per patient. The diary function was used 101 times and mostly contained information about current medical conditions (e.g. nausea, headache) and only 2 patients made use of the graphic data visualization function of the data app.

#### Survival

After an observational period of 6 months, 4 patients of the control group and 3 patients of the intervention group were alive. There was no statistically significant difference.

#### Discussion

Although most patients and family caregivers perceived the study concept positively, recruitment was unexpectedly difficult. Technophobia, as well as the immanent end of life, seemed to prevail over the anticipated benefits of the study and were stated as the leading obstacles by the patients. Furthermore, patients indicated that they feared data entry would be time-consuming. They also doubted usability of telemedical support and provided equipment. Therefore, only 7 patients (+ 1 family caregiver) were recruited for the intervention group. Out of these patients, 4 already owned a smartphone and/or laptop with Internet access. Most requests and data entries were performed by these 4 patients, implying that basic technical knowledge seems to be of importance. Similar findings were reported by Tieman et al. in-



dicating that the impact of compliance needs to be considered when assessing feasibility [18].

The excellent technical feasibility of the study should be emphasized. Due to numerous testing and careful development of the app, it did not fail once. The authors would like to point out the necessity of an engineer specialized in medical informatics. Dedication of the whole multidisciplinary team, regular team meetings and constant improvements are what ensured a smooth and continuous support for the patients. Reliable IT infrastructure and technical support are critical for telehealth models to be effective and will aid uptake.

Once the patients had trust in the telemedical support it led up to 22 requests. This trust is what seems to influence the better QoL in this study group. This finding correlates with the results of a qualitative study by van Gurp et al. on how outpatient palliative care teleconsultation facilitates empathic patient-professional relationships [19]. To further improve control of symptoms and provide greater confidence in the care given by the family members, weekly web conferences could be convenient [20, 21]. Interestingly, the frequency of data entry varied depending on the parameter and some study participants did not enter their blood pressure at all but made up to 60 entries concerning their nutrition. Therefore, the aim to establish effective telemedically augmented care was achieved. To our knowledge, this was one of the first telemedical studies in an extensive setting (i.e. technical effort, multidisciplinary team, study participants, real-life setting). The study indicated that telemedical support improves QoL of patients with advanced cancer. There is some evidence that telemedicine can be useful for patients with other chronic diseases as well [22, 23].

There are some limitations that need to be acknowledged. The number of study participants was relatively small and the recruitment was from a single palliative care unit. Therefore, further studies with larger sample size are required to confirm the positive effects of telemedical care. In future projects, other departments or hospices should be affiliated to the telemedical service. Additionally, mobile hospice teams can be involved. To gain better insights into overall survival, monthly survival follow-ups should be established. In the clinical routine, the main challenges will be a “tech savvy public”, funding, adequate settlement with health insurance providers and of course, technical support and data security. Telemedicine may even help to meet health system imperatives for improved service delivery within current budgets.

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### Compliance with ethical guidelines

**Conflict of interest** R. Nemecek, P. Huber, S. Schur, E.K. Masel, L. Baumann, C. Hoeller, H. Watzke, and M. Binder declare that they have no competing interests. We declare that we do not have a financial relationship with the organization that sponsored the research. Furthermore, we state that we have full control of all primary data and we agree to allow the journal to review the data if requested.

**Ethical standards** All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards. Informed consent was obtained from all individual participants included in the study.

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