






# Hello! How can I help you? The role of telephone consultation in palliative care for patients at home

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## ABSTRACT

This work aims to describe and analyse the telephone consultation (TC) for palliative care (PC) patients at home and their caregivers provided by a PC team in Portugal in 2020. This study is observational, retrospective, cross-sectional and correlational, conforming to the STROBE checklist. Records of calls between 01/01/20 and 31/12/20 and clinical process consultations were analysed for trend clearance, including cross-tabulations to look for associations between call characteristics. Call data included information on the caller, patient, problem, utility and choice of service. The data were analysed using the statistical program SPSS software (V.26). During 2020, 494 calls were answered. The majority of the contacts were made by relatives and answered by nurses. The main reason for the contact was symptom management. The TC solved 92.91% of the problems, allowing the patient to remain at home, which is associated with a decrease in the number of hospitalisation days and admissions to the emergency department. The identification of the causes that motivated the calls and who solved them allows us to anticipate some needs that may be less controlled at home. Call distribution time may help allocate human resources better. TC is a viable alternative to traditional hospital follow-ups.

**KEYWORDS:** home care services; palliative care; telephone.

## INTRODUCTION

In recent years, Information and Communication Technologies have become widespread in people's daily lives, including within healthcare settings (Pinto, Caldeira, & Martins, 2017). Patients in rural regions experience geographic barriers to accessing palliative care (PC) teams or hospice (Rainsford et al., 2017). Although the evidence is limited, some studies (Head, Schapmire, & Zheng, 2017; Zheng, Head, & Schapmire, 2016) suggest that telemedicine can expand access to PC in rural settings, improve the management of uncontrolled symptoms, facilitate communication between patient, family and PC team, increase patient and caregiver satisfaction and reduce costs.

Telehealth is widely acceptable for PC patients from different countries and with a wide range of age groups and

diagnoses (Jess, Timm, & Dieperink, 2019; Vitacca, Comini, Tabaglio, Platto, & Gazzi, 2019). Despite the history of the development of successful telehealth applications with hard-to-reach clients, the implementation of these technologies has been uneven (Solari-Twadell et al., 2022). However, in 2020, due to the COVID-19 pandemic, healthcare services were reorganised, many face-to-face consultations were cancelled with implications for patient access to primary care (Solari-Twadell et al., 2022), and many other difficulties arose as a result of mandatory confinement and/or contact isolation. Thereby, telephone consulting (TC) emerged as a relevant alternative to follow-up and support PC patients at home and represents a promising and low-cost alternative to face-to-face consultations. The rapid increase and wide adaptation of healthcare into care delivery models should be balanced

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**Conflict of interests:** nothing to declare. **Funding:** nothing to declare.

**Received:** 11/14/2023. **Accepted:** 01/18/2024.

against the perception by some patients and providers of its safety and value compared with in-person care.

In our study, a regional TC hotline was provided to PC patients at home to ensure their needs and to reduce the rate of hospital or emergency admissions. These patients were followed by a PC outpatient service from a rural and remote geographical area. This paper aims to describe the use of this regional TC hotline for PC patients at home and their families in Portugal. It will contribute to the literature and health decision-makers who can safely implement new, reliable, robust, and financially sustainable models of care/services.

## METHOD

An observational, cross-sectional and correlational study regarding the TC service done by a PC team.

### Sample

All telephone records retrieved from PC patients at home (or their caregivers/ relatives) were consecutively considered for analysis between 1 January 2020 and 31 December 2020.

### Instruments

Data was collected through a record sheet form, which captured information about the caller, the patient, the problem, and the orientation provided. The patient’s clinical process was also consulted.

The operators of the hotline were experienced nurses from the PC team, corresponding to 18 professionals. To standardise telephone service, a work methodology was created with guidelines for the approach (Figure 1).

At the end of the service, the nurse asked the user about the usefulness of the TC using a 4-point Likert scale (1-useless, 2-not very useful, 3-moderately useful, and 4-very useful).

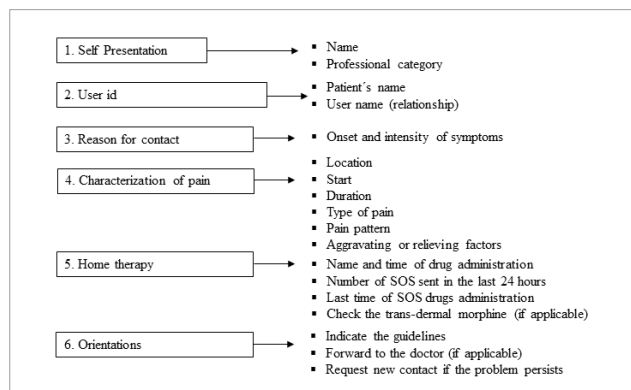


Figure 1. Schematic plan of the TC.

Then, an open-ended question was asked to determine the reason for using telemedicine.

## Procedures

The study was previously submitted to the board of directors of the service and the institution’s ethics committee. Approval was obtained from the Ethics Committee of the hospital, with the number 420/2020–C.A. The study included the TC users, who voluntarily agreed to participate and gave informed consent after explaining the purpose of the study to the nurse who answered the phone. The participants were told that the obtained information and the answers would be kept confidential. Data was codified using a code for each caller.

### Data analysis

Descriptive and inferential analyses were performed using SPSS software (V.26 for Windows®). Pearson’s correlation analysis examined the relationship between variables and tested the hypotheses. The ONE-WAY ANOVA test was used to compare the means in more than two groups. The statistical significance of the data was assessed at  $p < 0.05$ .

## RESULTS

### Phone call characterisation

Four hundred ninety-four calls were retrieved and included. The calls referred to a sample of 187 patients followed by the PC team during 2020, corresponding to an average of 2.64 phone calls per patient. According to Table 1, most

Table 1. Sociodemographic characteristics of the sample (n= 187).

Variables	n	%
Genre		
Feminine	103	55.08
Male	84	44.92
Age group		
< 50 years	7	3.74
50–65 years	20	10.70
65-80 years	62	33.15
≥ 80 years	98	52.41
Diagnosis		
Oncological disease	154	82.35
Nervous system disease	24	12.83
End organ disease	9	4.82

patients were more than 80 years old (52.41%) and were diagnosed with advanced cancer (82.35%), neurological diseases (12.83%) or end-stage organ failure (4.81%). A total of 6,500 minutes was recorded (13.16 minutes for call,  $SD \pm 5.01$  minutes). Most contacts to the hotline were made by caregivers/relatives ( $n=419$ ; 84.82%), healthcare professionals ( $n=60$ ; 12.15%) and some calls were directly performed by patients ( $n=15$ ; 3.04%).

About half of the calls received are resolved exclusively by the nurse ( $n=225$ ; 45.55%). Only 26.32% ( $n=130$ ) are attended exclusively by the doctor and are related to clarification of the patient's clinical situation, the therapy instituted, and requests for issuing medical prescriptions. The physician assumes a leading role in adjusting the therapeutic in a symptomatic lack of control, but then it is up to the nurse to explain the management of the therapeutic, namely about schedule, dose, and route of administration.

Although the TC was available 24 hours per day, seven days a week, the majority of calls (93.06%) were received during business hours on weekdays. The busiest periods were between 9:30 am and 10:00 am (20.57%), and the quiet period was between 2.30 pm and 3.15 pm (7.41%). After 6:30 pm, the contacts were residual. The period between 12:00 pm and 1:15 pm had a low call, and in the night, no telephone contact was made. The months of April and May stand out with the maximum number of calls answered respectively of 13.56% ( $n=67$ ) and 13.16% ( $n=65$ ) (Figure 2).

## Reason for the contact and recommendations

In 81.87% of the callers contacted the hotline during a crisis, symptomatic lack of control being the main reason, following request recipes (8.64%), questions/doubts (4.84%), and consultation rescheduling (2.59%). The most frequent problem was the aggravation or emergence of pain ( $n=150$ ; 25.91%), then food refusal ( $n=70$ ; 12.09%), insomnia and agitation ( $n=70$ ; 12.09%), and asthenia/

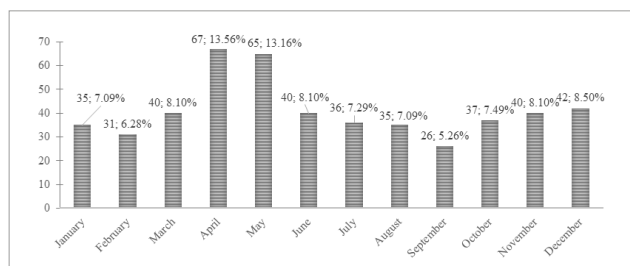


Figure 2. Monthly distribution of telephone contacts during 2020.

prostration ( $n=65$ ; 11.23%) were reported quite frequently (Figure 3).

Table 2 shows guidance provided by health professionals. Nursing clarified symptom management with dietary instructions for the treatment of nausea and/or vomiting, constipation, and diarrhoea and strategies for optimising fluid intake ( $n=80$ ; 10.72%). Optimising medication timing and good sleep hygiene strategies for patients with insomnia or restlessness is also a current guideline ( $n=60$ ; 8.04%).

The guidelines of the nurse team are related to teaching medication optimisation (SOS and/or new drugs) and care with the transdermal opioid patch ( $n=60$ ; 8.04%). In 44.91% of the contacts, the doctor made pharmacological adjustments due to the symptoms being out of control.

In the patients with advanced and terminal disease but which were not yet followed by the PC team, urgent episodes occurred due to pain ( $n=250$ ; 30.45%), dyspnoea ( $n=170$ ; 20.71%), nausea and vomiting ( $n=70$ ; 8.53%). After referral to a PC Team with TC, the main reasons for emergency episodes were dyspnoea ( $n=70$ ; 22.08%), fever ( $n=60$ ; 18.93%), asthenia ( $n=50$ ; 15.77%) and pain ( $n=43$ ; 13.56%) (Figure 4).

The number of patients referred to the urgency service (US) by the PC team during the TC represents only 4.05% ( $n=20$ ) and involves situations that require evaluation in the following hours. Additionally, 3.04% of the patients were referred to the palliative medicine inpatient service.

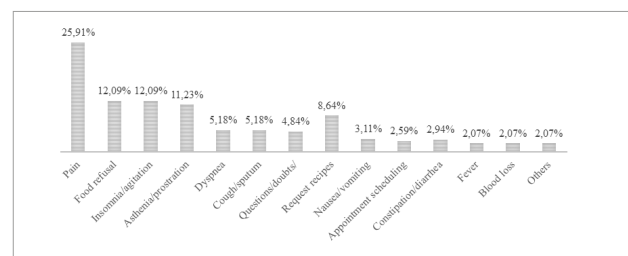


Figure 3. Reasons for telephone contact.

Table 2. Guidance provided by health professionals.

Guidelines	n	%
Therapeutic adjustment	335	44.91
Rescheduling the appointment date	87	11.66
Dietary instructions	80	10.72
Transdermal opioid dressing teachings	60	8.04
Management of sleep	60	8.04
Clarification of doubts/information	36	4.83
Guidance for end-of-life care	35	4.69
Teaching positioning, skincare and devices	33	4.42
Hospitalization in PC and/or SU	20	2.68

## Utility

All the users find the TC useful or very useful. The reasons pointed out were the following: trust in the team, speed and low cost of the service (30.01%); ease of access to hospitalisation in PC (29.05%); cancellation of face-to-face consultations (21.02%) and fear of resorting to US during the pandemic (19.92%).

## Hypothesis tests

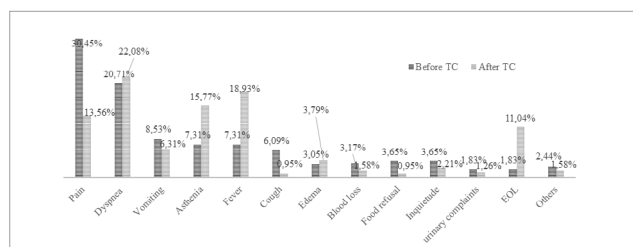
*H1: The number of hospitalisation days suffered a reduction in patients followed up in TC.*

*H2: The number of emergency episodes suffered a reduction in patients accompanied by TC.*

According to Pearson's correlation test, the number of hospitalisation days and urgency episodes before and after the existence of the TC are related ( $p < 0.001$ ). The correlation is strong and inverse. For patients followed in TC, there was a reduction in the number of hospitalisation days ( $r_p = -0.52$ ;  $p = 0.0001$ ) and the trips to the emergency service ( $r_p = -0.62$ ;  $p = 9.20 \times 10^{-8}$ ).

It is also noted that before the implantation of the TC, 88.11% resorted to the US with an average affluence of 4.39 ( $SD \pm 3.79$ ) episodes per person. After referral to a PC team with TC, the mean regressed to 1.69 episodes ( $SD \pm 1.99$ ) per person, meaning a 61.39% reduction in urgency episodes in users of TC.

There was, on average, a reduction of 71.02% in the number of internment days (Figure 5). However, an increase was observed in the number of days spent on the palliative medicine inpatient service.



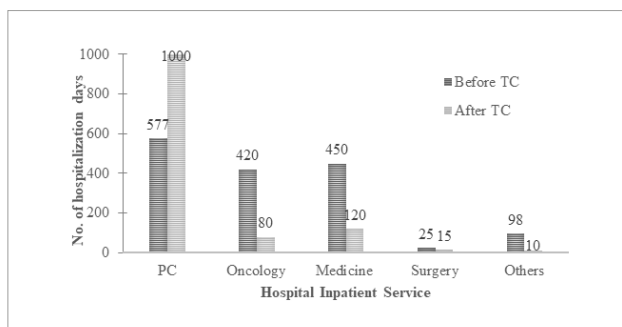
**Figure 4.** Reasons for going to the emergency department before and after TC.

*H3: Patients with oncological pathology are referred at an earlier stage of the diagnosis for a PC team than patients with non-oncological disease.*

According to Table 3 (ONE-WAY ANOVA), the type of pathology influences the average time for referral to a PC team. Thus, patients with oncological pathology are referred to a PC team at a stage closer to the moment of diagnosis of advanced and terminal illness. Conversely, patients with nervous system disease, such as dementia, are referred to a PC team at a much more advanced and limiting stage of the disease. On average, patients with illness advanced cancer are referred to a PC team 15.74 months earlier than patients with advanced nervous system disease ( $p = 3.99 \times 10^{-9}$ ).

## Financial analysis

The financial analysis with the implementation of the TC indicated an annual reduction of 68.203 euros, with a decrease in false visits to the hospital emergency department. This indicator was evaluated by considering the value of financing the emergency episodes (ACSS, 2022) and the expenses with the transport costs of the ambulances (Portugal, 2022) paid by the national health service. On the other hand, there was no increase in the cost of human resources since the team that performs the TC service is scheduled simultaneously to care for patients hospitalised in PC.



**Figure 5.** Number of days of hospital stay before and after the TC.

**Table 3.** Results of the application of one-way analysis of variance (ONE WAY ANOVA): Comparison between the types of pathology and the average time of referral to a PC team.

Diagnosis	Between groups	Mean (months)	F-Value	P-Value
Oncological	End-organ	-7.69	154	0.083
	Neurological	-15.74		$3.99 \times 10^{-9}$
End-organ	Oncological	7.69	9	0.093
	Neurological	-8.08		0.11
Neurological	Oncological	15.74	24	$3.99 \times 10^{-9}$
	End-organ	8.08		0.45

## DISCUSSION

The results of this survey provide the first detailed description of the TC service in PC existing in Portugal. The data show that the duration of the call and its daily distribution was adequate given the reason for the contact, almost triggered by the lack of symptomatic control. The hourly distribution of calls was similar to that described in other publications (Baird-Bower, Roach, Andrews, Onslow, & Curnin, 2016). Although this service is available 24 hours a day when the situation is not urgent, patients/families wait for the lunch break as a courtesy to make calls.

There is a lack of knowledge of the medical specialities in the hospital targeted by the study regarding the speciality of PC. Patients with cancer are the most referred to PC (Kydd & Sharp, 2016), and the referral of patients with terminal advanced disease did not occur at an earlier stage. The referral of other types of non-oncological pathologies that would benefit from PC is not so immediate (Lee et al., 2015; Wong et al., 2017).

The cancellation of non-urgent hospital consultations from March to May 2020 triggered the patients to find other types of health services. Thus, the TC emerged to respond to a need imposed by the pandemic. The TC showed a spike in calls between March and May, probably due to the cancellation of scheduled assistance activity in these months.

An average value of 13.16 minutes for a call stands out. Similar values were found in the literature (Phillips, Davidson, Newton, & DiGiacomo, 2008). Other studies indicated an average of 20 minutes to attend to patients with oncological disease (Williamson, Beaver, Gardner, & Martin-Hirsch, 2018; Williamson, Chalmers, & Beaver, 2015).

The deterioration of the physical condition was the main reason for the telephone contact, in line with other studies (Aranda, Hayman-White, Devilee, O'Connor, & Bence, 2014; Baird-Bower et al., 2016). Pain (25.91%) was the most frequently cited symptom within uncontrolled symptoms in the present study. Similar results are described in the literature (Strupp et al., 2017; Williamson et al., 2018). Other symptoms such as food refusal (12.09%), insomnia and agitation (12.08%) and asthenia/prostration (11.23%) were reported quite often. Nausea, vomiting, dyspnoea, food refusal, changes in bowel symptoms (constipation/diarrhoea) and insomnia are reported in several studies for telephone contact (Malmström et al., 2016; Strupp et al., 2017; Wong et al., 2016). With TC, there was a decrease of 16.89% in urgency episodes due to pain.

Dyspnoea continued to be a symptom of difficult control even after the implementation of PC, however, a pattern of lower urgency episodes was maintained with the TC.

The TC identifies the end-of-life (EOL) (4.69%) situations to motivate caregivers not to refer the patient to the US, prioritising the person's death in the comfort of home. This attitude emerges as a preventive measure against false medical emergencies. However, families are not prepared for this reality, so as soon as the EOL situation is signalled, the patient is referred for medical observation in the PC consultation, with the perspective of being admitted to the PC hospitalisation. These situations could be reversed if there were a continuous home-based PC team that reassured caregivers and families.

The guidance the PC team provides is similar to those indicated in other studies (Baird-Bower et al., 2016). These guidelines focus mainly on the patient's admission to PC hospitalisation, nursing care recommendations and doctor prescriptions.

The TC is very useful for caregivers because they know that there is a team always available and contactable, which provides great security and confidence. PC should, therefore, encompass and provide early intervention and social support programs to mitigate the burden on caregivers (Bachner, Morad, Sroussi, & O'Rourke, 2019; Robaye, Mormont, Lassaux, Janne, & Gourdin, 2018). Patients and caregivers point out that the thrust, low cost and ease of access to hospitalisation in PC are the main reasons for using the TC. Current energy costs should make us rethink the modalities of action, boosting the use of technological resources. On the other hand, the patients and families have the perception that the TC facilitates access to hospitalisation in PC. In this study, there was an increase in the number of days spent on the palliative medicine inpatient service.

The use of TC promotes a decrease in the number of days spent in the hospital. There was a lower mean of urgency episodes per user ( $4.39 \pm 3.79$  before CT versus  $1.69 \pm 1.99$  after CT,  $p = 9.20 \times 10^{-8}$ ). Other studies corroborate these results (Daugherty et al., 2018; Scarpi et al., 2019; Urban, He, Alfonso, Hardesty, & Goff, 2018) that indicate health gains with the introduction of PC versus general care, in terms of hospitalisation days, costs associated with care, number of episodes of urgency and requests for home consultations.

The results of this study are limited to this population. They cannot be generalised to all institutions and regions without geographic asymmetry. The mandatory confinement and the absence of other alternatives during this period may have somehow conditioned the demand and acceptability of the TC hotline.

## CONCLUSION

This study is a pioneer in proving, through hypothesis tests, the health gains for patients, families, health institutions and



society in general, with a reduction in the number of hospital stays and visits to the US. Political decision-makers should consider establishing TC teams in PC as a viable, promising, and assertive work modality in their strategic planning.

TC service hotline in PC is a viable, feasible alternative to traditional hospital PC in-patient follow-up. This study demonstrated the advantage of the TC in PC, namely a lower impact on the person than hospitalisation, allowing for a better quality of life. The indicators analysed favour their application, as they are a safe and effective way to keep people at home. On the other hand, TC emerges as an extremely important strategic planning activity in regions with high asymmetry and geographical isolation during the pandemic period.

## ACKNOWLEDGMENTS

A very special thanks to the PC team for the ULSTMAD – Palliative Medicine Service, for their availability, commitment and support.

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