MEDICAL UNIVERSITY OF VIENNA

FREQUENCY, PATTERNS AND OUTCOMES OF SPECIALIZED PALLIATIVE CARE PROVIDED WITHIN PALLIATIVE CARE UNIT – A RETROSPECTIVE DATA ANALYSIS

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ABSTRACT

Background: Palliative care is a holistic approach to care that strives to improve the quality of life of patients, that are suffering from a life-limiting illness, on a physical, psychological, social and spiritual level. Specialised palliative care (SPC) is performed by specialist clinicians and aims to coordinate services around the needs of patients by utilizing an interdisciplinary framework. This results in better patient outcomes, improved quality of life, reduces length of stay, decreases symptom burden and more. The referral of patients to SPC often depends on the diagnosis and symptomatology of the patient. However, studies show that some patients in need of SPC are not admitted due to their age, diagnosis or region. Hence, insight in transferal patterns is crucial and could assist future decision making.

Methods: In this retrospective study all patients that received a palliative care consult and then were further transferred to specialised palliative care unit within the palliative care unit in the General Hospital of Vienna from march 2016 to november 2021 will be included. First a descriptive analysis of the patient population followed by logistic and linear regression analysis will be performed.

Aim: The aim of this study is to describe the patient population that is transferred to specialised palliative care. Therefore, for instance their diagnosis, symptom burden or ECOG performance status will be analysed. Moreover, this study intends to identify factors that could predict a patient's outcome and help to enhance service provision in the future.

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1 BACKGROUND

Patients with life-threatening illnesses as for example cancer often require an individualized assessment of their preferences, goals and needs throughout their disease trajectory. Basic treatment alone cannot always fulfill these needs, which is why palliative care can be of use.(1)(2)

The WHO defines Palliative Care (PC) as a holistic approach to care that strives to improve the quality of life of patients that are suffering from a life-limiting illness, and of their care givers. This includes preventing and relieving physical, psychological, social and/or spiritual suffering of the patient at the end of life regardless of disease stage.(3) The incorporated care aims to adjust to the patient's and family's needs, beliefs, values and cultures.(4)

Studies show alleviation of symptoms like nausea, pain, fatigue and an enhancement of psychological and physical functioning. However, this only refers to a multi-disciplinary approach(1) as PC interventions performed by a single professional do not show an improvement in symptom burden. This highlights the importance of incorporating a multidisciplinary palliative care team.(3) Further, PC increases the chance of the patient dying at their preferred place (home death) and reduces the number of emergency department visits and the length of hospital stay.(5)

While Generalised PC is provided by non PC specialists and focuses on basic symptom control, Specialised Palliative Care (SPC) is performed by specialist clinicians.(1) SPC tries to coordinate services around the needs' of patients by utilizing an interdisciplinary framework and thereby improves the quality of their care. This results in better patient outcomes, improves satisfaction of patient and provider, lowers costs, reduces length of stay and increases the efficiency of staff work.(6) Furthermore, utilizing SPC improves the quality of life (QoL) of patients suffering from life-threatening illnesses, especially advanced cancer(7), and decreases physical symptom burden.(8) (9)

As SPS aims to be individualized, settings for SPC range from embedded PC clinics, free-standing PC clinics and home-based PC to telehealth PC.(10)

The benefits of PC and SPC are mostly studied when initiated early enough. To release maximum benefit PC has to be provided for at least 3-4 months.(3) However, studies show that the duration of PC by a multidisciplinary team is much shorter than recommended.(11) Most notably older people and patients with diagnoses other than cancer are at a disadvantage when referred late in their disease trajectory.(12)

The referral of patients to SPC often depends on the diagnosis and symptomatology of the patient. Studies show that patients with similar symptoms and problems like pain, appetite loss, decreasing physical functioning and fatigue are referred to a SPC service.(13) Other reasons for a referral to PC would be nausea, dyspnea, present symptom palliation review, insomnia, constipation or abdominal swelling.(14) Furthermore, it is reported that patients with a higher Eastern Cooperative Oncology Group (ECOG) score at time of diagnosis are correlated with being referred to SPC services. (15) Nevertheless, the admittance to SPC after referral seems to have a difference regarding region, diagnosis and age. As for example, older

patients and patients with haematological malignances are less likely to be admitted to SPC.(16) (17)

Traditionally the PC decision is made by the patient's oncologist or physician (oncologist-initiated referral). However, there exist other methods of referral such as automatic referral due to symptomatology or diagnosis. These methods may open the doors to PC for more patients but the capacity of PC is not always there and not all patients require SPC at that time.(10) A screening tool that can detect patients in need of SPC is the proxy assessment tool based on the NCCN (National Comprehensive Cancer Network). It includes ten items such as diagnosis, functional status, comorbidities, complications, distress and symptom management, and therefore triggers a PC consultation if a certain threshold is met.(18)

Yet, there still appears to be a lack of data and evidence regarding SPC as systematic reviews seem to show different results between studies. There is a demand of further research into the field of PC and SPC and the patients that require this care. (8) (19) (20) Furthermore, there have been no studies that look into referral patterns to SPC and patient characteristics and results, utilizing Austrian data.

2   STUDY OBJECTIVE

As the demand for PC increases and resources cannot always meet this interest(10), insight into the referred patient population and their characteristics and additionally their outcome is crucial.

The main objective of this study is to gain deeper knowledge about the patient population currently receiving SPC in Austria. Therefore, we aim to describe this patient population their characteristics and outcomes, for instance their diagnosis, symptom burden or ECOG performance status. We further aim to validate whether their characteristics match with the characteristics contained in the screening tool that can detect patients in need of SPC. Furthermore, we aim to identify factors that could predict a patient's outcome (such as length of stay and place of discharge) and help to enhance service provision in the future. Therefore, univariate and multivariate logistic regression analysis will be performed to determine factors that could predict outcomes. Confounding effects are to be minimized as further influencing variables are going to be analysed as well.

3   STUDY DESIGN

To attain the goal of this study, 171 patients that were transferred to SPC between March 2016 and November 2021 will be analysed retrospectively. Possible limitations of the study may be that this is a single center study and the results could be only generalised on other university centers because of similar patient profiles. Therefore, future research analysing data from other hospitals and centers could be useful in the field of palliative care. A potential information bias could be discussed as clinical data of relevance could possibly be missing and consequently not be included in the analysis.

4 PATIENT POPULATION

The study includes patients, which were transferred to the SPC unit after having received a PC council at general wards in the timeline March 2016 to November 2021. 903 patients received a council and 171 were further transferred to SPC. To be considered for inclusion, patients have to fulfil the criteria of transferal to the SPC unit and have to be at least 18 years of age. Patients, that solely receive a PC council and are not further transferred, will be excluded.

5 PARAMETERS

The table below shows the parameters that will be collected from each patient. First in order are patient characteristics, then several scores and then the outcome variables.

Table 1: Parameters

Parameters	Description	Categories/Units	Variable type
Patient age	Age at time of council	Years	Metric
Date of admission to hospital		Day.Month.Year	-
Date of admission to SPC		Day.Month.Year	-
Date of discharge from SPC		Day.Month.Year	-
Date of death		Day.Month.Year	-
Diagnosis	ICD10 Code	e.g. C25	Nominal
Diagnosis Groups	Divided into groups by "body sections"	Bone & Joint CA / Colon, Rectal & Anal CA / ENT CA / Esophageal, Gastric, Small Bowel & Liver CA / Hematological CA / Lung, Bronchial & Mesothelial CA / Mammary Gland CA / Ovarian CA / Pancreatic CA / Prostate & Kidney CA / Skin CA / Vulva, Vagina & Uterus CA / Other malignant diseases / Other non-malignant diseases	Nominal
Patient gender		Male/female	Nominal
Malignancy	ICD10 C__=malignant	Malignant/Non-malignant	Nominal
Place of discharge		Death/Home/Nursery Home/Transferal to other department	Nominal
Reason of referral	Reasons/symptoms that led to referral of patient	Pain/Dyspnea/Nausea/Vomiting/Mental Issues/Feeding Difficulties/Social Situation/Relief for Family Members/Caring Difficulties/Decline of General State of Health/Others	Nominal
Reason of request	Reason of council request	Takeover/Conciliary Care	Nominal

Time until Council	Date of admission to hospital – (minus) date of council	Days	Metric
Time between Council and Admission to SPC	Date of council – date of admission SPC	Days	Metric
Time between Council and Discharge	Date of council – date of discharge	Days	Metric
Referring station		Code of individual departments	Nominal
Referring station (by medical field)	Transferring stations divided into groups by medical fields	Cardiology, Angiology & Pulmonology / Dermatology / Endocrinology / Gastroenterology / Hepatology / General Surgery / Gynecology / Hematology & Hemostaseology / Infectiology / Nephrology & Dialysis / Oncology & PC / Orthopedics & Trauma / Radiooncology / Rheumatology / Others	Nominal
ECOG-Status	0=no limitations 5=death	0/1/2/3/4/5	Ordinal
0	Fully active, able to carry on all pre-disease performance without restriction		
1	Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g., light house work, office work		
2	Ambulatory and capable of all selfcare but unable to carry out any work activities. Up and about more than 50% of waking hours		
3	Capable of only limited selfcare, confined to bed or chair more than 50% of waking hours		
4	Completely disabled. Cannot carry on any selfcare. Totally confined to bed or chair		
5	Dead(1)		
Karnofsky Index (%)	0=death 100=no limitations	0/10/20/30/40/50/60/70/80/90/100	Ordinal
100	Normal ; no complaints ; no evidence of disease.		
90	Able to carry on normal activity; minor signs or symptoms of disease.		
80	Normal activity with effort; some signs or symptoms of disease.		
70	Cares for self. Unable to carry on normal activity or to do active work.		
60	Requires occasional assistance, but is able to care for most of his needs.		
50	Requires considerable assistance and frequent medical care.		
40	Disabled; requires special care and assistance.		
30	Severely disabled; hospitalization is indicated although death not imminent.		
20	Very sick ; hospitalization necessary; active supportive treatment necessary.		
10	Moribund; fatal processes progressing rapidly.		
0	Dead.(2)		
NCCN Score (adapted)		0-10	Ordinal
PiPS-A Survival 14 days	14-day survival prediction	Percentage	Metric
PiPS-A Survival 56 days	56-day survival prediction	Percentage	Metric
PiPS-A Survival	Survival prediction	Months / Weeks / Days	Nominal
Symptom Sum Score	Sum of all reasons of referral	0-11	Ordinal

Hospital mortality	In-hospital death or discharge	Death/Discharge	Nominal
Length of Stay	Date of admission to SPC– date of discharge SPC	Days	Metric

ICU: Intensive Care Unit
ENT: Ear Nose Throat Medicine
ICD10 Code: 10th International Classification of Diseases
CA: Carcinoma
ECOG Performance Status: Eastern Cooperative Oncology Group Performance Status
NCCN Score: Scoring Tool based on the PC guidelines of the National Comprehensive Cancer Network
PiPS-A Score: Prognosis in Palliative Care Study Score

6   METHODS

To identify the patient population, which received SPC, several steps are taken. First, data is collected from PC council requests and medical reports. A PC council is either written to request a referral of the patient to the PC department or to request conciliary care while the patient stays in the applying department. Both types of request can lead to a referral to the PC department. All council letters are stored in the respective patient files in the computer system AKIM (Allgemeines Krankenhaus Informations-Management).

Consequently, all identified PC council requests are entered into a Microsoft Excel 2019 file. Next, the referred patient population is filtered. For this sub-group additional patient data is extracted from the computer system AKIM, using patient files, medical reports, council letters, referral letters and nurse`s protocols. Patient data from March 2016 to August 2020 has already been extracted by a previous student (NB) and was readily available. Therefore, only patient data between the time period September 2020 until November 2021 has to be extracted additionally.

7   STATISTICAL METHODS AND JUSTIFICATION OF THE NUMBER OF PATIENTS

The program IBM SPSS Statistics version 27.0.1 is utilized to evaluate, calculate and visualize the results.

7.1   RESEARCH QUESTIONS

One aim of this study is to gain deeper knowledge about the patient population currently receiving SPC in Austria. By getting insights into current transferal patterns and to see in how far they relate with published SPC screening tools.

Another aim of this study is to see in how far SPC outcomes (hospital mortality and length of stay) are predictable based on available patient characteristics. This insight will help to target future SPC transfers on those patients which potentially benefit from SPC most.

The specific research questions are:

Primary Research Questions:

- What are the characteristics of PC patients currently receiving SPC in Austria?
- Is it possible to predict SPC patient outcomes (hospital mortality, length of stay) based on the available parameters, such as patient characteristics?

Secondary Research Questions:

- How do patient characteristics of patients receiving SPC in Austria relate with the available SPC screening and prognostic tools?
- Do patients with high scores on available screening tools have different SPC outcomes compared to those with low scores?

7.2 PRIMARY RESEARCH AIMS

7.2.1 DESCRIPTION OF PATIENT POPULATION

For each available patient characteristics descriptive analysis will be performed. Categorial data will be analysed using absolute and relative frequencies and then will be compared to each other through Qui-square-test. Mean, median, standard deviation, minimum and maximum will be calculated for metric variables. To visualise the results, boxplots, bar graphs and histograms will be applied.

7.2.2 PREDICTION OF SPC OUTCOMES

Univariate and multivariate (step-wise forward selection, for significant results in the univariate analysis) logistic regression analysis is conducted. The dependent variable is hospital mortality; all parameters but the calculated scores (due to correlation with other variables included in the scores) are added as independent variables. The results of the logistic regression analysis are presented with the odds ratio, a 95% confidence interval, the regression coefficient and the pseudo-R^2 (Nagelkerke) and visualized with forest plots.

Univariate linear regression analysis is performed with the continuous parameter length of stay for all variables but the calculated scores (see paragraph above). Before conducting the analysis, we test for normal distribution of the residuals and outliers. If this is not given, the length of stay variable is logarithmized (log10). Significant parameters of the univariate analysis are further put into a multivariate linear regression analysis (stepwise forward approach). The findings of the linear regression analysis are depicted by the regression coefficient, the R^2 (coefficient of determination) and the p-value. The results of the univariate analysis are visualized with the aid of scatter plots.

A two-sided significance level of alpha < 0.05 has been set for all statistical computations.

7.3 SECONDARY RESEARCH AIMS

The adapted NCCN score, the Symptom Sum Score and the PiPS-A-Scores will be calculated for every patient and then presented numerically and graphically. It is further examined if patients with high scores have different SPC outcomes compared to those with low scores. For the adapted NCCN score we additionally calculated how many patients have reached the trigger point of 4.

To examine if patients with high scores on these screening tools have different SPC outcomes (hospital mortality, length of stay) compared to those with low scores, the following tests (or nonparametric alternatives) will be calculated.

Table 2: Tests and Alternatives for Screening Tools

Screening Tools		Length of Stay (metric)	Hospital Mortality (dichotomous)
Adapted NCCN Score	Ordinal	Spearman	Mann Whitney U
PiPS-A-Survival	Nominal	T-Test / Mann Whitney U	Chi^2 / Fisher`s Exact
PiPS-A-Survival56	Metric	Pearson / Spearman	T-Test / Mann Whitney U
PiPS-A-Survival14	Metric	Pearson / Spearman	T-Test / Mann Whitney U
Symptom Sum Score	Ordinal	Spearman	Mann Whitney U

7.4 JUSTIFICATION OF THE NUMBER OF PATIENTS

This study includes a sample size of 171 patients, because data concerning councils was collected from March 2016 onwards. Until November 2021 903 patients received a council and 171 patients got referred to SPC.

7.5 MULTIPLE TESTING

As correlations tests are explorative in this study, correction for multiple testing is not necessary.

8 PRIVACY

All patients are consecutively numbered, the analysis of the data occurs pseudo-anonymized and digit coded. Only authorized staff have access to the data, which is saved on a password-protected computer in a lockable room in the Department of Palliative Medicine of the General Hospital of Vienna. There already exists an ethics approval until the 7th of July 2022, as a different diploma thesis is working on the same data set.

9 BENEFIT-RISK ASSESSMENT

On the one side, included patients do not take a direct benefit of the study. On the other side, as this is a retrospective analysis of their data no risk can be detected either. The only possible risk, the leaking of sensitive patient data, is minimized by the restriction of access and the pseudo-anonymization. In total, this retrospective study can be categorized as being low risk for patients.

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11 APPENDIX

11.1 ABBREVIATIONS

PC	Palliative Care
SPC	Specialised Palliative Care
QoL	Quality of Life
ECOG	Eastern Cooperative Oncology Group
NCCN	National Comprehensive Cancer Network
GHV	General Hospital of Vienna
AKIM	Allgemeines Krankenhaus Informationsmanagement (General Hospital Data Management)