

Univerzita Karlova 3.Lékařská fakulta

Autoreferát disertační práce

Vliv paliativního nemocničního týmu na finanční nákladnost a kvalitu péče o pacienty v závěru života.

Impact of a hospital palliative care team on costs and quality of care of patients at the end of life.

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Souhrn česky

Tato disertační práce srovnává péči v závěru života v nemocnici při zapojení paliativní péče a bez ní. Druhá část práce se zaměřuje na zlepšení kvality života nemocných používáním validovaných nástrojů s využitím pacientem reportovaných dat. **Cíl** Cílem první studie je srovnání kvality péče a nákladovosti terminální hospitalizace při zapojení paliativní péče a bez ní. Cílem druhé studie je provést překlad, kulturní adaptaci pro české prostředí a validaci nástroje IPOS-renal. Metodika První studie byla deskriptivní studií případů a kontrol. Sledovali jsme rozdíl hospitalizačních nákladech a v kvalitě péče mezi skupinou pacientů zemřelých bez paliativní intervence a s ní. V druhé studii jsme přeložili IPOSrenal do češtiny a kulturně ho adaptovali s použitím kognitivního testování. V průběhu validační studie jsme testovali vnitřní konzistenci, spolehlivost, validitu přeloženého dotazníku a jeho korelaci na zlatý standard v nefrologii, KDOOL-SF dotazník.

Výsledky V první studii jsme ukázali, že průměrné denní náklady jsou při integraci paliativní péče tři krát nižší (4392.4 Kč za den = 171.3 EUR) než bez ní (13992.8 Kč za den = 545.8 EUR) a rozdíl byl pravděpodobně způsoben nížším počtem dnů strávených v intenzivní péči (16% vs. 33% hospitalizačních dnů). V druhé studii validace IPOSrenal činil Cronbach's alpha 0.72 pro vnitřní konzistenci, intraclass koeficient 0.84 pro test-retest spolehlivost a 0.73 pro spolehlivost mezi různými hodnotiteli. Korelační koeficient mezi IPOS-renal a KDQOL-SF 1.2 byl mezi 0.4-0.8 pro většinu dotazníkových otázek a tím byla prokázaná dobrá konvergentní validita.

Shrnutí: V první studii jsme prokázali, že integrace paliativní péče v závěru života v nemocnici šetří nemalé prostředky. V druhé studii jsme prokázali, že česká verze IPOS renal je validním a spolehlivým nástrojem a doporučujeme ho používat v klinické praxi k rutinnímu hodnocení symptomů a problémů u nemocných s pokročilým chronickým onemocněním ledvin.

Abstract

This dissertation thesis describes the end-of-life care in hospital setting and compare quality of the dying phase with and without specialist palliative care support. The second part of the thesis focus on quality of care improvement by using patient reported outcome measures(PROMS).

Aims The first study aimed to compare costs of terminal hospitalization and quality of care between the group of patients with and without support of a palliative care team.

The second study aimed to provide translation, cultural adaptation and validation of IPOS-renal measure.

Methods The first study was a descriptive retrospective case-control study. We explored the difference in daily hospital costs between patients who died with and without the support of the hospital palliative care team. In the second study the IPOS-renal was translated to Czech and culturally adapted using cognitive interviews. During the validation phase, internal consistency, reliability and convergent validity was tested with correlation to Kidney Disease Quality of Life Survey-Short Form 1.2.

Results In the first study we showed that the average daily costs were three times lower in the palliative group (4392.4 CZK per day = 171.3 EUR) than in the non-palliative group (13992.8 CZK per day = 545.8 EUR), and the difference was probably associated with the shorter time spent in the ICU (16% vs. 33% of hospital days). In the second study Cronbach's alpha was 0.72 for internal consistency and the intraclass correlation was 0.84 for test-retest reliability and 0.73 for inter-rater reliability. The IPOS-r correlated with KDQOL-SF 1.2 and had a rho between 0.4-0.8 for most of the IPOS-r items, showing good convergent validity.

Conclusion We showed that the integration of the palliative care team in the dying phase can be cost saving in the first study. In the second study we proved the Czech IPOS-renal is a valid and reliable tool and we recommend it's use in clinical practice.

1. Introduction

Palliative care has evolved over the last few decades from a philosophy of care for dying patients to a professional discipline with expertise in symptom management, psychosocial and spiritual care, caregiver support, patient-clinician communication, complex decision-making, and endof-life care. (Jacobsen, 2011) There are many benefits of palliative approach for people with advanced disease described in literature. (Temel, 2011; Zimmermann, 2014; Barkitas, 2009) According to many foreign studies, integration of palliative care in hospital can improve symptom management, promote quality of life, help patients with better understanding of their situation, and ensure that medical care is provided according to patient's preferences.(Gaertner, 2017; Hearn, 1998; Higginson, 2002; Zimmermann, 2008) This thesis focus mainly on end of life hospital care, because more than 60% of all deaths in the Czech Republic occur in an acute hospital setting

according to national data of Institute of Health Information and Statistics of the Czech Republic. (Švancara,2022)

In the practical part, I have conducted two research projects.

The first one was a retrospective case-control study called Dying matters. The study was focused on description of economical aspects and quality of care provided in the end of life and potential benefits of a hospital palliative care team in the tertiary university hospital. According to international recommendations, guality of care and symptom burden of patients with advanced disease should be assessed by validated patient reported outcome measures (PROMS) and it is feasible to use PROMS also in very advanced disease. (Clapham, 2021; Kane, 2017; Higginson, 2012) There is only one PROM validated in the Czech Republic for palliative care population, and it's called Integrated Palliative Oucome Scale (IPOS).

(Vlčková,2020) As it was validated mainly on patients with oncologic diseases, it is not appropriate for patients with non-oncologic diagnoses. Patients with renal failure are the most complex and have many unmet needs. (Combs,2015; Cohen,2006)

In the second project, I provided translation, cultural adaptation and validation of Integration Palliative Outcome Scale-renal (IPOS-r) to improve symptoms assessment and quality of life of the palliative patients with renal failure.

2. Aims and objectives

2.1. The dying matters study

The aim of our study was to describe the complexity of the dying phase in the tertiary university hospital in Prague, not only quality of care and dying, but also patients' preferences and the healthcare costs.

Objective 1: Our study aimed to determine whether integration of the hospital palliative care team at the

end of life can prevent the use of burdensome diagnostic and therapeutic procedures, prevent transitions to intensive care and lower healthcare costs.

Objective 2: We aimed to find out whether there were any differences in the documentation of EoL preferences between patients dying with and without the support of the hospital palliative care team.

Objective 3: We explored if having limitations of lifesustaining treatments, prognosis, and preferences documented can influence time spent in the ICU.

2.2. Translation, cultural adaptation and validation of IPOS-renal to Czech

The aim of our study was to bridge this gap of no patients reported outcome measure for palliative renal patients .

Objective 4: We aimed to provide a translation, cultural adaptation, and validation of the Czech IPOS-r and to assess it's psychometric properties.

3.Methods 3.1. The dying matters study

Design: We used a case-control observational retrospective study design with a mixed-methods approach. We retrospectively analysed and documented data from paper and electronic medical records of terminal hospitalizations. In quality of care assessment we provided qualitative content analysis of medical records.

Setting: The Faculty Hospital Kráovské Vinohrady is a tertiary university hospital in Prague.The hospital's palliative care team plays a leading role in the implementation and development of specialist hospital palliative care in the country. **Participants:** A total of 213 patients were supported by the hospital palliative care team during the dying phase. They were matched with similar controls from all deceased patients who were not supported by the team. Routine data from the National Death Registry and National Registry of Hospital Activity were used for the matching. Propensity score matching was used to control for variation in age group (decades), sex, Charlson comorbidity index, and diagnosis recorded on the death certificate.

Data collection: Data were collected from paper and electronic medical records. When the qualitative data were analysed, content analysis of the written data was carried out. Economic data were collected from hospital bills to the insurance companies. Patients' preferences, prognosis, and limitation of life-sustaining treatments and the words used for the description of the dying phase were extracted and transcribed verbatim.

Variables: Calculation of the total daily costs of a terminal hospitalization and determination of their difference between the control and clinical group were the primary outcomes. The most exact estimate of the daily costs is possible by counting all the costs of diagnostic and therapeutic procedures (monetary value paid for the medical performance) by insurance company) and adding all prices of separately charged drugs and materials. The secondary outcomes were the length of the terminal hospitalization, days in the ICU, the use of intravenous (IV) antibiotics, chemotherapy and radiotherapy in the last month, and the number of costly diagnostic procedures [Computerized Tomography (CT)/Magnetic Resonance Imaging (MRI) scans]. When the semi-qualitative data (documentation of dying phase) were analysed, content analysis of the written data was carried out. Patients' preferences were grouped into bigger themes with similar meanings. The prognosis and limitation of life-sustaining treatments were

documented when the exact time frame was found in medical records.

Data analysis: The geometric mean and logarithmic transformation of hospital costs were used for power analysis. A total of 195 patients in each group were needed to demonstrate a cost difference of 20% (10,000.00 CZK = 392 EUR) between the groups with a significance level of 0.05 and a power of 0.8. The statistical significance of differences between the clinical and control groups was tested by Fisher's exact test for categorical variables and the Mann-Whitney U test for numerical data.

3.2. Translation, cultural adaptation and validation of IPOS-renal to Czech

This was a mixed-method multicentre study conducted in five facilities in the Czech Republic **Concept analysis:** The first step was a brief literature review of all concepts used in the IPOS-r followed by the translation and cultural adaptation of the measure. Forward and backward translation of IPOS-r was made by two translators and sent to the POS team in the United Kingdom for the final check. The final version was used for cognitive interviews. We performed in-depth qualitative interviews to check the views of patients and staff on the outcome measure,and the final IPOS-r version was created using patients' and staff's views of the measure.

Validation: The validation phase was conducted in one outpatient clinic and four dialysis centres across the Czech Republic on adult patients with advanced kidney disease (eGFR < 15 ml/min/1.73m²) who were treated with haemodialysis, home haemodialysis, peritoneal dialysis, or conservative management. Doctors, nurses, or social workers completed their version on the same day independently from the patients. Measurement data were collected at three time points. At the first time point (T1), patients completed the Czech IPOS-r patient version and the Czech KDQOL-SF 1.2, and health care staff

independently completed the Czech IPOS-r staff version. At the second time point (T2), patients completed the Czech IPOS-r three days after and at the third time point (T3), the Czech IPOS-r was completed one month after the first questionnaire, and the patients answered an item asking if their situation had changed since their last completed the IPOS-r. During the third assessment, patients also completed the time needed to complete the IPOS-r. Statistical analysis: The internal consistency was determined via Cronbach's α for the total score of the IPOS-r. For test-retest reliability we computed the level of perfect agreement between T1 and T2 for each item with quadratic weighted kappa and test-retest reliability of the IPOS-r total score was assessed with intraclass correlation coefficients (ICCs). Inter-rater reliability was determined for patient and staff ratings at the first time point using weighted kappa, level of agreement for every item, and ICCs for the total score.

Sensitivity to change: We compared mean changes based on the global change rating, which

was assessed by patients during the third assessment after one month.

Validity: To assess the convergent validity of the IPOS-r, we used Spearman correlation to the KDQOL-SF 1.2. We matched IPOS-renal items with KDQOL-SF items according to the meaning so they were covering the same construct.

4.Results

4.1. The dying matters study

Costs and the group differences: 73 outliers (17%) had hospital costs exceeding twice the mean value. More outliers (47 patients, 64%) with extremely expensive hospitalizations were in the non-palliative group. The average daily costs were three times lower in the palliative care group (4,392.4 CZK = 171.3 EUR per day) than in the nonpalliative care group (13,992.8 CZK = 545.8 EUR per day, p≤0.001). Chemotherapy and radiotherapy in the last month of life were used similarly. We also did not observe any significant

differences in IV antibiotic use. The use of diagnostic MRI and CT scans was also similar.

Hospitalization: Integration of the palliative care team was associated with significantly shorter terminal hospitalizations (mean=14.3 days in the palliative care group vs 18.4 in the non-palliative care group, p≤0.001). Patients who received palliative care interventions spent less time in the intensive care (16% of the hospital days in the palliative care group vs. 33% in the non-palliative care group, p≤0.001).

Documentation of the dying phase: Twice as many patients in the palliative care group (62.4%) had the dying phase documented in their medical records compared to the non-palliative care group (30.5%, p<0.001).

Documentation of preferences: Patients had their preferences documented fifteen times more often in the palliative care group (49.3%) than in the non-palliative care group (3.3%, p<0.001)

Documentation of prognosis: The palliative care group had a prognosis documented ten times more often (37.0%) than the non-palliative care group (3.7%, p<0.001)

Limitation of life-sustaining treatments: Twice as many patients in the palliative care group (66.6%) than in the non-palliative care group (34.7%) had limitation of care in their records.(p<0.001)

Documentation of family support: Family support was documented six times more often in the palliative care group (83.5%) than in the control non-palliative care group (13.1%, p<0.001)

4.2 Translation, cultural adaptation and validation of IPOS-renal to Czech

The final sample consisted of 88 patients who were treated with haemodialysis (70.5%), home haemodialysis (5.5%), peritoneal dialysis (3%), and conservative management (21%).

Cognitive interviews: Ten qualitative interviews with renal patients and ten interviews with the health care staff were performed. The interviews covered all questions on the measure. We checked for their comprehensibility, appropriateness, and relevance for the interviewees.

Internal consistency: Cronbach's alpha for the total score of 24 items was 0.72 (Tavakol, 2011)

Reliability: Test-retest reliability was computed for all items and for the total score. Most of the kappa coefficients (22 of 24) were above 0.4; only for the items vomiting and information needs was the value below 0.4. The ICC for the total score was 0.84.For 11 items out of 24, we found agreement between the staff and patient assessment weighted kappa > 0.4, with the highest level of agreement for pain (0.66) and changes to the skin (0.56). The lowest level of agreement was found for anxiety (0.17). For the total score, the ICC was 0.73.

Sensitivity to change: Patients who reported positive changes after one month had a positive

mean change in the total scores of eight points and patients who reported negative changes showed a negative eight-point difference between T1 and T3.

Validity: Convergent validity was assessed using Spearman correlation with items from KDQOL-SF and most of the correlations were in the range of 0.4–0.8. Only questions about family anxiety, practical problems, information needs, and time wasted on appointments did not have a significant correlation with items from the KDQOL-SF.

Appropriateness and acceptability: The IPOS-r was feasible and acceptable for the patients and the staff. The average time to complete the measure was nine minutes.

5. Discussion

5.1. The dying matters study

This study shows that the integration of the hospital palliative care team during the dying phase has the potential to reduce healthcare costs. The cost savings were associated with a lower number of

extremely expensive hospitalizations and fewer days spent in the ICU in the palliative care group.

This study also shows that integration of the hospital palliative care team during the dying phase can bring improvement of the quality of care. Twice as many patients in the palliative care group had the dying phase documented in their medical records compared to the non-palliative care group. This may be caused by the fact that end-of-life discussions are not a common part of the Czech culture and are taboo, but they are the standard part of a palliative care consultation. Patients in the palliative care group had prognoses documented in medical records more often than patients from the control group. Knowing prognosis could have had a significant influence on preferences and advance care planning. Significantly more dying patients had their EoL preferences discussed and documented in medical records including their preferences for invasive medical interventions and limitation of lifesustaining treatments. This could have been the

reason for fewer days spent in the ICU in the palliative care group. The large sample size (n=213) increased the strength of the results. The limitations are also present, the one centre study had limited external validity and including just dying patients could have been a source of measurement bias. The semi-qualitative assessment of the dying phase in medical records and the words used to describe the dying process could have been biased by the researchers.

5.2.Translation, cultural adaptation and validation of IPOS-renal to Czech

Patient-reported outcome measures (PROMs) are very useful tools to capture patients' experience with the disease and health care. (Raj, 2017; McLaren, 2021) The IPOS-renal measure does not have any validated translations except the English, Danish and Portuguese versions.The Czech translation and cultural adaptation of IPOS-r were performed successfully, and no major changes were required after cognitive interviews except for adding a description of restless leg syndrome. The Czech IPOS-r version is short, and the time needed to complete it is acceptable for patients and staff. The IPOS-r showed sufficient internal consistency, excellent test-retest reliability, and moderate agreement between the staff and patient assessment, especially in physical domains. In some of the physical domains, namely, weakness, nausea, poor appetite, difficulty sleeping, restless legs and sore or dry mouth, the study showed lower than moderate inter-rater agreement, so clinicians should focus on the assessment of these symptoms, as they seem to be overlooked.

Weighted kappa values for inter-rater reliability were poor only for anxiety; lower than moderate agreement was seen in most non physical domains (feeling at peace, depression, ability to share feelings with family, time wasted on appointments), which are more difficult to assess. We were able to demonstrate good convergent validity for IPOS-r when compared to the KDQOL-SF 1.2, most of the correlations were in the range of 0.4–0.8, which indicates good convergent validity.

This study has several limitations. In 12 out of 100 patients, IPOS data were not completed, which is common in end-of-life research. The renal patients in our study were very stable, with only 14 of 88 reporting a change in their health status after one month, so we could not calculate sensitivity to change by a statistical test.

6.Conclusion

6.1 The dying matters study

Financial resources can be a significant barrier to the development of palliative care not only in the Czech Republic, but also in many other countries. The supporting evidence that hospital palliative care is associated with lower utilization of intensive care and potential cost savings can help when advocating and negotiating with stakeholders about payment of this service.

6.2. Translation, cultural adaptation and validation of IPOS-renal to Czech

The process of translation and cultural adaptation of the IPOS-r was successfully provided, and our study proved that the Czech IPOS-r is a responsive, reliable, and valid tool. Our results recommend the use of the IPOS-r measure in clinical practice.

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