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# How Do You Engage End-users in the Co-design of Out-of-hours Palliative Care Services?

**Oral presentation: Christine Low Siew Lan (AU)**

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**Introduction**
Co-designing healthcare services with end-users is a complex intervention that requires careful planning and execution. While the co-design approach can help address service delivery issues during out-of-hours palliative care (OOH PC), it can be challenging to initiate. The aim of this study is to investigate how to involve and engage end-users in the co-design of out-of-hours palliative care services in the community.

**Methods**
Semi-structured interviews were conducted with international researchers and service organisers who have experience in using a co-design approach for developing OOH PC services or other palliative-related services. Interviews were transcribed and analysed using NVivo by means of thematic analysis.

**Results**
Twelve researchers and seven organisation representatives were interviewed. Six key principles were identified, which are 1) Determine end-users needs and build their capability and capacity to participate, 2) Recognise and develop strategies to encourage diverse and inclusive representation of end-users, 3) Develop and refine shared co-design values, 4) Leverage from a suite of activities, methods and techniques to support authentic participation, 5) Develop ways to support end-users throughout the co-design process, and 6) Plan for closure, evaluation, translation of learnings and sustainability of the co-design process.

**Conclusion**
The findings of this study provide valuable insights for researchers and service providers who aim to involve and engage end-users in the co-design of OOH PC services. These six principles are interconnected and complementary, offering a holistic guide that recognises the complexity of co-design and provides insights and practical implication.

**Keywords**
palliative, out-of-hours, co-design, service design

# Palliative Care Phases (PCP) in cancer patients receiving specialist palliative home care (SPHC): A mixed methods study

**Oral presentation: Andrea Kobleder (CH)**

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**Background**
There is no data available on Palliative Care Phases (PCP) in specialist palliative home care (SPHC) in Switzerland. The present study aimed to conduct an in-depth analysis of burden and needs of outpatient palliative care cancer patients and family caregivers in each PCP and to determine the corresponding resource use.

**Design and Methods**
The study utilized a convergent mixed-methods design. 91 adult cancer patients and 54 family caregivers, who were cared for within SPHC, participated in the study. We collected quantitative data on medical and sociodemographic characteristics, symptoms, burdens, needs and resource consumption. Moreover, we conducted 20 semi-structured interviews with patients and family caregivers and 3 focus group interviews with the nursing staff from SPHC. For data analysis we applied t-tests, factorial ANOVA, repeated measurement ANOVA and qualitative content analysis. Data was merged using joint display tables.

**Results**
We found a significantly higher symptom burden, more unmet needs, and higher resource consumption in the unstable, deteriorating and terminal phases compared to the stable phase. The interviews revealed a potentially overlooked vulnerability of patients and family caregivers in the stable phase. The core themes of each phase were: ambivalence (stable), anxiety and uncertainty (unstable), the tangible end of life (deteriorating), clarity (terminal) and finality (bereavement).

**Conclusions**
The study emphasizes the vulnerability and complex burdens and needs of outpatient cancer patients and their family caregivers across all phases. Specific care concepts and funding principles need to be developed to ensure access to SPHC, especially in the stable and the bereavement phase.

# Specialized palliative telemedicine for patients with advanced cancer at home: a pilot study.

**Oral presentation: Geana Kurita (DK)**

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**Background**

This study proposes a specialized palliative care (SPC) intervention enriched with a dyadic psychological intervention for patients with advanced cancer and their caregivers delivered by telemedicine at home. It also integrates the primary healthcare sector and oncologic team in the therapeutic plan. Primary aim is to investigate the intervention effects on the patients' health-related quality of life. Secondary outcomes include dyadic coping patient-caregiver and caregiver burden, among others.

**Methods**

A pilot RCT has been conducted at a comprehensive cancer centre. Patients' inclusion criteria: ≥18 years, solid organ cancer, no curative treatment, cognitively able to participate, ≥ 1 symptom/problem with score ≥ 3 at EORTC QLQ-C30. Sample= 66 patients. Patients indicates closest informal caregiver (≥18 years), who is invited to participate. Intervention: first SPC appointment within 5 days from randomization and regular video follow-ups according to the SPC team's assessment, as well as 2-5 dyadic psychological intervention sessions. Monthly multidisciplinary conferences are organized by SPC team, which includes oncology team, general practitioner, and district nurse to discuss the therapeutic plan. Control group: standard care. Assessments at inclusion, and after 2 weeks and 1/2/6 months.

**Results**

Forty-two breast cancer patients have been included. Dropouts: intervention=0, control=4. Caregiver: intervention=20, control=12. Challenges have been low participation of other healthcare professionals at the multidisciplinary conferences and few episodes of unstable telecommunication system. Data collection is expected to be completed in July 2024.

**Conclusion**

This pilot study is helping to determine feasibility of a model that can inspire organization of future SPC resources.

# Performance status and albumin predict survival from last line chemotherapy for pancreatic and other gastrointestinal cancers

**Oral presentation: Olav Dajani (NO)**

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**Background/aims**

Patients with pancreatic (PAN) and other gastrointestinal (GI) cancers often receive systemic treatment near end of life, thereby increasing the potential for overtreatment. Consequently, there is a need for better prognostic tools that can improve clinical decision-making. We compared the utility of performance status (PS), albumin (alb), CRP, body mass index (BMI) as prognostic factors for overall survival from start of last-line chemotherapy for PAN and GI cancers.

**Methods**

The PALLiON trial was a cluster-randomized controlled trial that assessed a complex intervention with time- vs needs-based referrals to palliative care and use of PROMs. The trial included patients eligible for treatment with last-line chemotherapy at 12 Norwegian hospitals (2017-2022). Hospitals were stratified by size. We applied Cox regression survival models in a secondary analysis to identify the usefulness of prognostic factors among these patients, comparing PAN vs GI cancers.

**Results**

The PALLiON trial included 189 PAN and 286 GI cancer patients. There were no significant baseline differences between the groups in age, sex, PS (2+ vs 0-1), BMI (<18.5 vs ≥18.5), alb (<35 vs ≥35 g/L), CRP (>10 vs ≤10), or hospital size (small/medium/large). Adjusting for age, sex, BMI, and hospital size, we found that PS 2+ and alb < 35 g/L predicted a shorter survival in both PAN and GI cancers, whereas CRP > 10 predicted shorter survival only in GI and not in PAN cancer.

For PAN, combined CRP and alb (mGPS) score of 2 (vs mGPS 0) gave a 68.7% chance of shorter survival (HR 2.20 [1.26-8.83]; p=.005), whereas PS 2+ (vs PS 0-1) gave a 78.4% chance of shorter survival (HR 3.63 [1.60-8.24], p=.002).

For GI, patients with mGPS 2 (vs mGPS 0) had a 70.8% chance of shorter survival (HR 2.42 [1.40-4.19], p=.002), whereas PS was non-significant in final analysis (p=.72).

BMI did not add strength to the models neither for PAN nor for other GI cancers.

**Conclusion**

At start of last-line chemotherapy, PS 2+ and low alb predict shorter survival in PAN, whereas mGPS predicts shorter survival in other GI cancers.

# Perspectives of physicians treating lung cancer patients on the clinical use of outcomes: A qualitative study

**Oral presentation: Abel García Abejas (PT)**

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**Background**

Using patient-reported outcome measures in scales can help personalize patient care pathways, including the frequency and type of clinical review. We aimed to elucidate the perception of the outcomes of physicians who treat lung cancer patients and the impact on their quality of life to establish relationships (related to the patient, the social and family environment, and the diagnosis and treatment), in addition to relating them to multidimensional aspects of the patient's experience. Additionally, we also identified barriers and facilitators to using the outcome measures.

**Methods**

We conducted 16 semi-structured interviews. Its collecting expert opinions on physicians' perceptions of their patient's outcomes and the most relevant risk variables. A qualitative analysis was performed.

**Results**

Three primary groups were identified in the interview analysis: patient-related, social, and family environment, and diagnosis and treatment. No direct relationship was discovered between the perception of outcomes by physicians and experiences of patients and caregivers.

**Conclusions**

PROMs need to be implemented in the daily routine of clinical, physicians generally focus on clinical outcomes rather than patient-centered outcomes, their experiences, and needs. The digitization of PROMs can facilitate their use. We perceive as barriers can also be facilitators, depending on several factors (health literacy, digital literacy, and socioeconomic level). The use of PROMs is relevant, provided there is feedback, and the outcomes are subsequently managed with the patient. ePROMs could improve these situations, this type of digital instrument could not address some dimensions, such as spiritual care. Physicians can focus their attention on each patient.

# Barriers and Facilitators when Applying Electronic Patient-Reported Outcome Measures through a Cluster Randomized Trial: A Qualitative Study

**Oral presentation: Terese Solvoll Skåre (NO)**

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**Background**

Use of electronic patient reported outcome measures (ePROMs) could facilitate a more systematic approach to symptom assessment in cancer care. However, implementing these tools remains a challenging task for health care professionals (HCP).

**Objective**

To explore physicians' and nurses' perceptions of facilitators and barriers when applying ePROM (Eir) through a cluster randomized trial. In addition, we aimed to explore any effect use of ePROM had on HCPs workflow.

**Methods**

Oncologists and study nurses who were involved in applying Eir to the intervention sites were invited to participate. Six in-depth interviews and one focus group interview with 9 HCPs were conducted. Data analyses were guided by Framework Analysis, and The Consolidated Framework for Implementation Research was applied in the deductive stages of the analysis.

**Preliminary Results**

The analysis revealed three themes describing barriers to or facilitators for successful use of ePROM in a hospital setting: "Management anchoring; changes start at the top", "Willingness to invest; new eras come with a cost", and "Framework conditions; decisive for the outcome". In addition, our study revealed differences in how physicians and nurses evaluated the value Eir had for both patients and HCPs.

**Preliminary Conclusion**

Applying ePROMs in clinical practice seems to be a challenging task due to the complexity of the process. Focusing on the benefits for both patients and HCPs could be of major importance as the implementation requires time consuming changes.

# Quantitative Sensory Testing in patients with pain due to cancer

**Oral presentation: Morena Shkodra (IT)**

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**Background**
Quantitative sensory testing (QST) is a psychophysical method used to assess small and large fibers function in the somatosensory pathway. While it has been used to quantify sensory abnormalities in different neuropathic pain conditions, little is known on the assessment of cancer pain through QST and its discriminatory ability in neuropathic cancer pain (NcP) cases.

**Aim**
Our aim was to assess the somatosensory profile of patients with cancer pain and assesses QST's ability to distinguish NcP patients.

**Methods**
This is a cross-sectional study conducted in a palliative care and pain outpatient clinic. Patients with cancer pain intensity ≥ 3 (Numerical Rating Scale 0-10) were eligible. A QST based on the protocol of the German Research Network on Neuropathic Pain (DFNS) was conducted on the painful and a non-painful control site. Paired T-tests were run to assess intrapersonal differences in the overall group. Kruskal Wallis and unequal variance independent sample t-tests were used to compare patients with and without NcP.

**Results**
98 patients were enrolled from August 2020 to March 2023. QST data showed sensory impairments in the overall group, characterized by; hyposensitivity to thermal stimuli, both for cold and warm ($p< 0.001$), hyperalgesia to hot pain stimuli ($p=0.0369$) and pressure pain stimuli ($p=0.000$), and presence of allodynia in 14 patients ($p< 0.001$). In the comparison of patients with and without NcP cold hypoesthesia ($p=0.0032$), warm hypoesthesia ($p=0.0018$), pressure hyperalgesia ($p=0.02$) and allodynia ($p=0.0001$) were more specific to the presence of NcP.

**Conclusions**
QST discriminated well between oncological patients with and without NcP.

# The prevalence of opioid misuse in adult patients with cancer: A systematic review and meta-analysis

**Oral presentation: Tazha Ako (DK)**

**Authors:** Tazha Ako[1], Mark Puch Ørnskov[1], Camilla Lykke[2,3], Per Sjøgren[2], Geana Paula Kurita [1,2,4]

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**Background/Aim**

Opioid misuse has gained attention and concern in chronic non-cancer pain and questioned whether it also could be of concern in patients with cancer. This systematic review aimed to investigate the prevalence of opioid misuse in adult patients with cancer.

**Methods**

The search strategy incorporated terms related to cancer, opioid misuse, and prevalence. PubMed, Embase, PsycInfo, and CINAHL were systematically searched from inception to July 2023, with a specific focus on prospective studies with adult patients. Articles were examined for prevalence, study characteristics, and quality using the Joanna Briggs Institute checklist for prevalence studies. Additionally, meta-analysis was conducted in a subgroup of articles to evaluate the risk of opioid misuse.

**Results**

Out of 585 abstracts, six articles met the inclusion criteria. These studies reported a broad spectrum of opioid misuse prevalence ranging from 5.7% to 84%, with associated misuse risks varying from 2.4% to 35.4%. The subgroup meta-analysis yielded a pooled prevalence of opioid misuse risk at 12.3% (95% CI: 0.8-36.3; I2= 98.4%, 95% CI: 97.2-99.1). It is worth noting that these studies exhibited significant diversity in definitions of misuse, methodologies, assessment tools, and other characteristics. Only one study met all quality criteria outlined in the checklist.

**Conclusion**

Few studies characterized by high heterogeneity were identified. While the findings suggest a range of opioid misuse and opioid misuse risk prevalence rates, they also emphasize the need for more comprehensive studies in patients with cancer.

# Why Norwegian oncologists do not use diagnosis codes for malnutrition

## Poster presentation: Lisa Heide Koteng (NO)

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### Background

Patients with cancer are at high risk of malnutrition. Although relevant ICD-10 codes are important in healthcare statistics and planning, these are rarely used in Norwegian cancer clinics. Understanding the barriers to using the diagnosis codes for malnutrition is important and may improve nutritional practice for patients with cancer.

### Aim

To explore oncologists' perspectives of barriers to using the ICD-10 codes for malnutrition.

### Methods

A qualitative study was conducted using focus group interviews with oncologists (n=14) from four Norwegian hospitals. A semi-structured interview guide consisting of five main topics guided the dialogue.

### Results

Few oncologists were familiar with the diagnostic codes for malnutrition, and none used them systematically. The oncologists considered the codes to be inapplicable in clinical practice, partly due to the complexity of many diagnostic criteria. The oncologist did not use specific tools to assess malnutrition but asked patients about their weight, weight loss, food intake and appetite. The most important concern for the oncologists was to identify patients in need of nutritional treatment, and diagnosis codes were perceived as unnecessary for providing good patient care. Proposals for increased code use were economic incentives, increased collaboration with clinical dietitians and a digital system for automated coding.

### Conclusion

Oncologists prevent and treat malnutrition in patients with cancer, but do not use the ICD-10 diagnosis codes for malnutrition. Oncologists reported that both complex diagnostic criteria and its lack of significance for the nutritional treatment of patients limit code use.

# Examining variability in intra-hospital patient referrals to specialized palliative care: A comprehensive analysis of disciplines and outcomes

**Poster presentation: Eva Katharina Masel (AT)**

**Authors:** Claudia Fischer[1], Katharina Dirschmid[1], Eva Katharina Masel[2]

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**Background**
In Austria, access to specialized palliative care (SPC) is limited and there is a lack of well-defined referral criteria. As a result, it is unclear which hospitalized patients with supportive care needs receive SPC, as well as the reasons and timing of referral, and outcomes.

**Methods**
This retrospective cohort study included patients who received a palliative care needs assessment between March 2016 to November 2021 and were subsequently admitted to the palliative care unit (PCU) of the largest academic hospital in Austria. Using demographic and clinical data and standardized referral forms including patient concerns, differences in PCU referrals and deaths were analysed using descriptive statistics and logistic regression analyses.

**Results**
Of the 903 patients assessed, 19% were admitted to the PCU. Of these, 94.7% were diagnosed with cancer. Patients diagnosed with lung cancer (18%) or breast cancer (13%) were the largest referred groups compared to hematological cancer patients (3%). The most common reason for referral was pain (61%), followed by nutritional problems (46%). There were no significant differences in referral times. The vast majority of patients died in the PCU (78.4%), but significant differences were observed between cancer diagnoses. In addition, the referral reasons “pain” (OR=2.2), or “nutritional problems” (OR=2.4) and “end-of-life care” (OR=6.5) were significantly associated with death in the PCU.

**Conclusion**
Our study highlights the imbalance in SPC access and outcomes in Austria, emphasizing the importance of timely palliative care integration across all disciplines for effective advance care planning and dignified end-of-life experiences in PCUs.

# Use of peripherally inserted central venous catheters and midline catheters in palliative care cancer patients. A systematic review.

**Poster presentation: Eva Gravdahl (NO)**

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**Background**

Peripherally Inserted Central Catheters (PICCs) and Midline Catheters (MCs) may offer convenient intravenous access, but evidence to support their place in palliative care is limited. This review aimed to assess catheter indications, utilization, complications, dwell-time, and patient experiences in palliative care cancer patients.

**Methods**

A systematic search for studies on catheter utilization for supportive or symptom treatment was conducted in Medline, Embase, CINAHL, Web of Science, Cochrane, and CENTRAL databases. Studies with a study population or a subgroup of palliative care cancer patients were included. Study quality was assessed using the Effective Public Health Practice Quality assessment tool.

**Results**

Of 7631 unique titles, 17 articles were examined in detail, all published between 2002 and 2022. Median catheter dwell time varied from 15 to 194 days; the longest when utilized for home parenteral nutrition. For pain and symptom management the typical duration was 2-4 weeks, often until the patient's death. Complication rates were minimal, with thrombosis, infections, and occlusion ranging from 0 to 2.46 incidents per 1000 catheter days. In studies from palliative care services, patients reported minimal distress during procedures and high user satisfaction. Quality of life assessments post-procedure improved, possibly influenced by concurrent specialist palliative care provision. All studies were assessed to be of moderate or weak quality.

**Conclusion**

PICC and MC are safe and valuable tools in palliative care cancer patients who would benefit from intravenous access for symptom management. Further studies are needed to clarify indications for PICC or MC in palliative care.

# Patient reported symptom levels in long-term survivors after brain metastases

## Poster presentation: Olav Erich Yri (NO)

**Authors:** Guro Lindviksmoen Astrup [a,b,c], Astrid Telhaug Karlsson [b,c], Marie Birketvedt [a], Stein Kaasa [a,b,c,d], Olav Erich Yri [a,b,c,d]

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**Background**

With improved anti-cancer treatments, cancer patients survive longer. Even after being diagnosed with brain metastases (BM), some patients may live more than two years after diagnosis. We describe patient characteristics at diagnosis and patient reported symptom levels of 43 patients at time of BM diagnosis and at ≥2 years of follow-up.

**Methods**

Totally, 912 consecutive patients diagnosed with BM from solid tumors were included in a prospective study. Patient reported symptoms were assessed using EORTC QLQ-C15-PAL and BN20 questionnaires at inclusion and monthly for 1 year. Patient alive ≥ 2 years after BM diagnosis were invited to a follow-up assessment with the same questionnaires. Scores at inclusion and at ≥ 2 years (T2) follow-up were compared using paired samples t-test.

**Results**

43 patients responded to long-term assessment. At diagnosis, median age was 61 years (35-84); 42% male. Primary cancers were lung cancer (44%), melanoma and (23%), breast cancer (23%). 69% had ECOG 0-1, 63% had one BM, 66% had controlled extracranial metastases and 75% had a targetable mutation. Initial treatment was stereotactic radiotherapy (44%), surgery (33%), whole brain radiotherapy (16%) and systemic treatment (7%). Patients reported the highest symptom scores for fatigue, sleep disturbance and drowsiness both at inclusion and at T2. Scores for global quality of life (QoL), physical functioning and sleep disturbances improved at T2.

**Conclusions**

Long-term survivors represent a heterogeneous population. At T2, patients reported improved scores for global QoL, physical functioning and sleep disturbances. Levels of fatigue and drowsiness did not improve.

# Living with brain metastases – A qualitative study about patient- and family members' coping strategies

**Poster presentation: Daniela Lillekroken (NO)**

**Authors:** Daniela Lillekroken[1], Asta Bye[1,2], Liv Halvorsrud[1], Olav Erich Yri[2], Torunn Wester[2,3], Marianne Hjermstad[2,3], Nina Aass[2], Stein Kaasa[2], Tonje Lundeby[2]

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**Background**

Brain metastases (BM), a feared complication of cancer, can cause significant morbidity as well as emotional and social burdens for patients and their family members. To deal with troublesome feelings and difficulties in such situations, people use different coping strategies that can change over time.

**Aim**

To explore coping strategies in patients with BM and their family caregivers from the time of diagnosis and the following two and four months.

**Methods**

Patients were recruited from a large perspective Norwegian study, the *BrainMet.* The sample included 38 participants, comprising 20 patients with a first diagnosis of BMs and 18 family members. All were interviewed three times; right after the diagnosis, then after 2 and 4 months. Data were analyzed using thematic analysis.

**Results**

The patients and their family members used both similar and different coping strategies. Both patients and their family members used hope and to some extent positive thinking. The patients additionally used active avoidance to deal with stressors related to the disease, substituted by a focus on everyday life, positive thinking, and trust the BM treatment. The family members used problem-solving coping strategies such as seeking information, planning the future, and organising their lives.

**Conclusion**

Given the diversity in coping strategies, it is imperative for healthcare professionals to adopt a person-centered approach that addresses individual needs. We suggest that tailored information provision, coupled with emotional support can enhance the quality of life for both patients and their family members.

# Perspectives of physicians treating lung cancer patients on the clinical use of outcomes: A qualitative study

**Poster presentation: Abel García Abejas (PT)**

**Authors:**

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**Background**

Using patient-reported outcome measures in scales can help personalize patient care pathways, including the frequency and type of clinical review. We aimed to elucidate the perception of the outcomes of physicians who treat lung cancer patients and the impact on their quality of life to establish relationships (related to the patient, the social and family environment, and the diagnosis and treatment), in addition to relating them to multidimensional aspects of the patient's experience. Additionally, we also identified barriers and facilitators to using the outcome measures.

**Methods**

We conducted 16 semi-structured interviews. Its collecting expert opinions on physicians' perceptions of their patient's outcomes and the most relevant risk variables. A qualitative analysis was performed.

**Results**

Three primary groups were identified in the interview analysis: patient-related, social, and family environment, and diagnosis and treatment. No direct relationship was discovered between the perception of outcomes by physicians and experiences of patients and caregivers.

**Conclusions**

PROMs need to be implemented in the daily routine of clinical, physicians generally focus on clinical outcomes rather than patient-centered outcomes, their experiences, and needs. The digitization of PROMs can facilitate their use. We perceive as barriers can also be facilitators, depending on several factors (health literacy, digital literacy, and socioeconomic level). The use of PROMs is relevant, provided there is feedback, and the outcomes are subsequently managed with the patient. ePROMs could improve these situations, this type of digital instrument could not address some dimensions, such as spiritual care. Physicians can focus their attention on each patient.

# A Comparison of Palliative Care Delivery between Ethnically Chinese and Non-Chinese Canadians in the Last Year of Life

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**Importance**

Ethnically Chinese adults' use of palliative care (PC) in North America are under studied.

**Objective**

To compare the use and delivery of PC in the last year of life between ethnically Chinese and non-Chinese adults.

**Design, Setting, and Participants**

Population-based cohort study using linked health administrative data from adults who died between January 1st, 2012, and October 31st, 2022 in Ontario, Canada.

**Exposures**

Chinese ethnicity.

**Main outcomes and measures**

Elements of physician-delivered PC, including model of care [generalist; specialist; consultative, no PC], timing and location of initiation, and type of physician at initial consultation.

**Results**

The final study cohort included 963,667 non-Chinese (49.3% female, 76.6±14.8 mean age, 14.2% rural residence) and 23,043 ethnically Chinese adults (48.7% female, 78.6±14.8 mean age, 0.8% rural residence). Chinese ethnicity was associated with higher likelihoods of using specialist (adjusted odds ratio [aOR] 1.53, 95%CI: 1.46-1.60) and consultative (aOR 1.32, 95%CI: 1.26-1.38) over generalist models of PC, compared to non-Chinese patients. Chinese ethnicity was also associated with a higher likelihood of PC initiation in the last 30 days of life (aOR 1.07, 95%CI: 1.03-1.11), in the hospital setting (aOR 1.24, 95%CI: 1.18-1.30), and by specialist PC physicians (aOR 1.33, 95%CI: 1.28-1.38).

**Conclusions**

Chinese ethnicity was associated with a higher likelihood of consultative and specialist models of PC delivery in the last year of life compared to adults who were non-Chinese. These observed differences may be due to later initiation of PC in hospital settings that suggest opportunities to initiate early, community-based PC to support ethnically Chinese patients with serious illness.

# Family carers' experiences with brain metastases - a longitudinal qualitative study

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**Background**
Living with brain metastasis (BM) causes distress for patients and family carers. Patients report a wide range of physical, social and psychological problems that affect daily life for them and their families. Despite the high prevalence of BM, little is known about the experiences of family carers. This qualitative study explores how family carers of BM patients perceive the information and communication about diagnosis, the health care services provided, and how their lives are affected by the BM.

**Method**
This was a prospective qualitative study with individual semi-structured interviews. Participants were interviewed three times; shortly after the BM diagnosis, and then after two and four months. A total of 40 interviews with 18 adult family carers (13 spouses, 2 adult children, 2 siblings) were conducted. Transcripts were analysed using a reflexive thematic analysis. A trajectory matrix was developed for the longitudinal design, searching for overarching themes over time as well as changes in the themes identified.

**Results**
For many family carers the BM diagnosis was experienced as particularly frightening, given that the metastases were located in the brain.

Family carers felt that they lived in a rapidly changing, chaotic and unpredictable situation. They reported working nonstop to coordinate family life, the patient's health care follow-up, and to maintain a sort of normality in daily life. The situation affected their relationship with the patient, especially daily life activities and communication.

The need for information was extensive among most family carers. They emphasized a need for more information about treatment and prognosis to be able to plan for the future. This information need remained high through all interviews.

**Conclusion**
Being a family carer of a patient with BM implies extensive practical, emotional and psychosocial challenges. The need for continuous information is particularly high, and health care providers should tailor their information to the individual recipient. Palliative care, with a person-centred approach and systematic follow up of the needs of family carers, should be introduced in an early stage.

# Projects from the pre-seminar

## January 31st

PRC European Palliative Care
Research Centre

# Evolution of patients attended in an outpatient palliative care clinic integrated in the functional unit of head and neck cancer: observational prospective cohort study

**Presenter: Maria Labori Trias (ES)**

**Introduction**: Early palliative care intervention has been proposed as an effective measure for the control of patients with advanced cancer. Patients with head and neck cancer (HNC) are known to present high symptom burden and alteration of important functions (phonation, swallowing, breathing) related to the disease as well as to oncological treatments.

**Hypothesis**: The integration of a palliative care (PC) outpatient clinic into the functional unit of HNC with a periodic intervention of the PC specialist can improve symptomatic control of HNC patients.

**Objectives:**

- Primary objective: Evaluate the evolution of symptom burden of patients visited at the PC outpatient clinic (between the first and third visit).
- Secondary objectives:
    - Assess average pain control (between the first and third visit).
    - Analyse the characteristics of patients with recurrent-metastatic and locally advanced HNC and compare their evolution over time.
    - Compare the quality of life (QoL) of HNC patients at the first visit, two months, and four months.
    - Identify factors related to better symptom control.

**Methodology**: This is a prospective observational cohort study conducted in a PC outpatient clinic integrated into the HNC functional unit. Patients with HNC at any stage of the disease have been recruited at the first visit during a period of two years and one-year follow-up has been performed. Demographic, clinical, and therapeutic variables and their evolution have been evaluated in this period. The study variables and different scales used to evaluate symptoms, emotional area, functional situation, and complexity were collected at different time points: first visit, second and third visit (during a three-month period), and then at six, nine, and twelve months. The EORTC QLQ-C30-H&N35 was administered at the first visit, and at two- and four-months follow-up. Changes in symptom control (evaluated with ESAS-r list and pain using items from the BPI questionnaire), analgesic treatment, QoL, as well as cancer disease status and anti-cancer treatment, will be analysed.

**Expected results**: Patients are expected to present a reduction of symptom burden and an improvement in pain control and other symptoms evaluated during the follow-up in the outpatient PC clinic. A better knowledge of the evolution of HNC patients and the identification of factors related to symptom control will lead to identify areas of improvement in the follow-up of these patients.

**Current status:** The recruitment period has been between January 2020 and December 2021. A total of 118 patients have been recruited. Statistical analysis is expected to start soon.

# Multicenter observational study on fentanyl blood concentrations during the conversion of administration route for pain control in cancer patients

**Presenter: Gemma Sanclemente Juarros[1] (ES)**

1 Palliative Care Service. Institut Català d'Oncologia. Barcelona, Spain.

**Introduction**: Pain is a common symptom in patients diagnosed with cancer. Opioids are the treatment of choice in moderate to severe pain. Intravenous route is useful for a rapid titration, and when pain control is achieved, it is necessary to convert opioid to a less invasive route. In the case of fentanyl, it is administered by a transdermal patch. After applying the patch there is a delay of a few hours to reach therapeutic blood levels. There is limited evidence on the optimal method of converting intravenous to transdermal fentanyl, aiming to prevent pain worsening and the occurrence of adverse effects.

**Objective:** The objective of this study is to analyse safety and efficacy of fentanyl conversion from continuous intravenous to a transdermal route in patients with cancer pain.

**Material and methods / design:** A multicentric prospective observational study will be performed. Patients with cancer pain admitted to the Palliative Care Unit who are being treated with continuous intravenous fentanyl and who present a good pain control, they will be offered to be included in the study. After signing the informed consent, the conversion between routes will be performed according to our center protocol. Transdermal fentanyl patch will be applied using a conversion rate of 1:1; at the time of patch administration, intravenous infusion will be halved for six hours, and stopped thereafter. At the time of patch applying, and 3, 6, 12, 18, 24 and 30 hours thereafter, we will collect a blood sample for fentanyl concentration measurement, and we will record pain intensity and adverse effects related to the drug. Other variables that will be collected are sex, age, primary neoplasm, nutritional status (body mass index), functional status (ECOG, Palliative Performance Scale), blood tests (kidney and liver function, albumin serum concentration), and the use of other drugs, specifically those with effects on the central nervous system and cytochrome P-450 inductors or inhibitors. Given that our procedure is different from published studies, we consider the study to be exploratory. Considering the number of patients admitted in the three participating centers and the percentage of patients admitted that require the conversion from intravenous to transdermal route, we calculated a sample size of 100 patients within a recruitment period of one year.

**Expected results**: The main objective of the study is to provide scientific evidence, which is currently scarce, on the procedure of converting intravenous to transdermal fentanyl in such a way that allows pain control while avoiding the onset of adverse effects. It also aims to study the kinetics of fentanyl in the change of administration route, and to determine if there are clinical and analytical factors that may alter such kinetics and thus may be taken into account when performing this procedure.

# Prospective Analysis of Anticancer Treatment Prevalence, Costs, and Impact in Patients with Advanced Cancer

**Presenter: Gudrun Kreye[1,2] (AT)**

*1) Karl Landsteiner University of Health Sciences, Krems, Austria*

*2) Department of Internal Medicine II, Clinical Division of Palliative Medicine, University Hospital Krems, Krems, Austria*

**Introduction**

There is a wide range of literature on recommendations for anticancer treatment in cancer patients' last phase of life. We aim to investigate the use of established and new treatments at the end of life in Lower Austria. To prevent futile treatment, we will evaluate the effectiveness of a guideline-based assessment tool in a pilot project in the Krems district.

**Methods**

The planned study will span one year and consist of two phases. In part a, we will collect data prospectively from patients with newly diagnosed metastasized cancer or progressive disease, based on local practice. Inclusion criteria are patients with newly diagnosed metastasized disease or progressive disease before decision of further treatment options. In part b, we will use a guideline-based assessment tool to make treatment decisions and evaluate the need for palliative care services. We then will compare data from both cohorts, part a and part b, respectively. The evaluation will include patients' characteristics, outcomes, and the proportion of patients receiving anticancer treatment in a palliative setting. Furthermore, the study will assess the proportion of patients receiving more than three lines of systemic palliative anticancer treatment and routine assessments for both anticancer treatment and Palliative Care needs. The costs of Oncology Services, anticancer treatment, and Palliative Care Services for patients with advanced cancer will be evaluated during the study period. Finally, the study aims to estimate the survival rates of patients receiving anticancer treatment compared to those not receiving treatment. Through these evaluations, the study aims to provide insights into the local practice, outcomes, and costs associated with advanced cancer care and treatment decisions. Before starting palliative anticancer treatment, all patients with either first signs of advanced disease or tumor progression at the UH Krems will be screened whether they are fit for anticancer treatment by established assessment tools (see appendix). In addition, patients will be screened for Palliative Care needs. Provider based decision for application of anticancer treatment and referral to Palliative Care services will be documented. In addition, all patients will be asked if they want to provide information on their quality of life via the EORTC-Quality of Life C30 (Version 3) survey.

### Inclusion and exclusion criteria

All adult patients (age > 18 years) who present first signs of advanced cancer or progression will be included in the prospective analysis by intention to treat. All patients who are willing to fill out the EORTC-Quality of Life C30 (Version 3) survey will be included in this part of the study.

### Primary and secondary study endpoints

Primary endpoint:

- Difference in number of patients receiving anticancer treatment by using local practice screening versus assessment tools in addition to ECOG-based decisions at the UH Krems

Secondary endpoints:

- Provider-based decisions on anticancer treatment
- Provider-based decisions on referral to Palliative Care Services
- Assessment of prevalence, costs, and impact of anticancer treatment and Palliative Care Services in a palliative setting
- Assessment of quality of life in patients with advanced cancer before decision on further treatment options

### Aim

The novelty of this research lies in evaluating not only the use of chemotherapy and radiotherapy at the end of life, but also the use of newer treatment options in the last days of life. Another novelty is the plan to perform a detailed cost analysis of treatment at the EOL for patients with advanced lung cancer. The use of assessment tools and the integration of palliative care will be investigated for the first time. The study aims to describe factors influencing treatment decisions and assess the benefits of palliative care for patients and healthcare costs.

The overall aim of these research projects is to gain better understanding of treatment decision making and to evaluate the feasibility of assessment tools in the decision-making progress to improve EOL care for patients with advanced cancer.

# BEreavement SupporT for Families

## Tailored implementation of evidence-informed family end-of-life and BEreavement SupporT (BEST for Family) in acute palliative care: A mixed-methods study with health professionals and family members

**Presenter: Torsten Schwalbach[1,2] (CH)**

1 Institute for Implementation Science in Health Care, Faculty of Medicine, University of Zurich

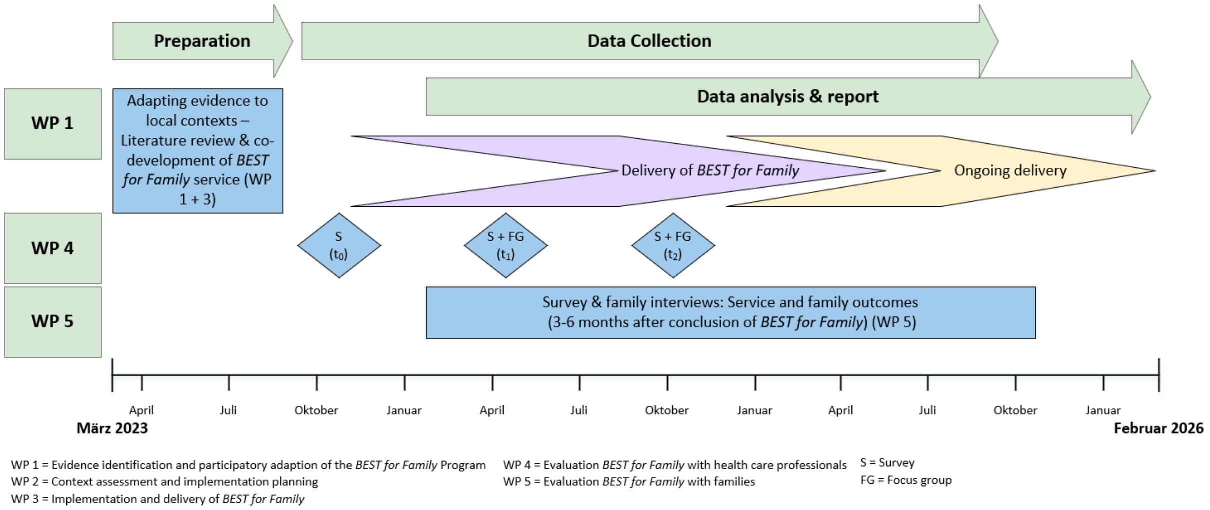
2 Center of Clinical Nursing Science, University Hospital Zurich

### Background

Persons with life-limiting illnesses die most often following a lengthy period of illness during which they receive family support and care by an interprofessional health care team. Family caregiving followed by the loss of the close other are stressful and incisive experiences that may impact negatively their physical and mental health. Bereavement support is an essential part of palliative care. The research evidence and guidance recommend a risk- and needs-oriented, tailored approach to bereavement support, which has not yet been systematically adopted to the Swiss context. Bereavement support has been found beneficial for families. Therefore, consistent delivery is required.

### Study overview

The *BEST for Family* project will adopt an evidence-informed family bereavement support program in two specialized palliative care services in German speaking Switzerland. In an iterative and participatory approach, the evidence will be adapted to the specific context, implemented and evaluated. The project is split into five work packages (WP) (Figure 1 below).



WP 1 = Evidence identification and participatory adaption of the *BEST for Family* Program
WP 2 = Context assessment and implementation planning
WP 3 = Implementation and delivery of *BEST for Family*
WP 4 = Evaluation *BEST for Family* with health care professionals
WP 5 = Evaluation *BEST for Family* with families
S = Survey
FG = Focus group

*Figure 1: Flowchart PhD Project*

## Aims and research questions

The aim of the project is to develop, implement and evaluate a contextually adapted and tailored bereavement support program for families in adult specialized palliative care.

My PhD project will focus on the participatory adaptation of the evidence (WP 1) and the evaluation of the program with families and health professionals (WP 4 + 5). My main research questions include:

- What is the impact of bereavement support on family health, wellbeing and coping with death and loss in adult specialized palliative care across all settings?
- What are the quality and health benefits of bereavement support practices from bereaved family members' and health professionals' perspectives?
- What are the mechanisms and level of achieved integration of bereavement support in palliative care at 6 and 12 months of active implementation?

## Methods

To identify qualitative and quantitative evidence describing the impact of bereavement family support on family outcomes in palliative care, I will conduct a rapid systematic mixed methods review (WP1) (Garritty et al., 2021; Stern et al., 2021). In the review I will identify comprehensive quantitative and qualitative data, analyze and merge it, using a convergent segregated approach (Lizarondo et al., 2020). The results will provide a better understanding of how specific bereavement support interventions work for whom and in which setting, directly inform the participatory development of the *BEST for Family* bereavement support program and thus ensure that it is based on the best available evidence.

In WP 4 I will evaluate the implementability and implementation of *BEST for Family* with health professionals (40-50 participants). Implementation processes and outcomes (e. g. feasibility, acceptability and appropriateness of the intervention, skills in and quality of family care) will be analysed with a one-group pre-mid-post design (t0-2) with embedded qualitative process evaluation (Patton, 2015). To understand the integration process of the *BEST for Family* program in-depth, I will use the Normalization Process Theory (May et al., 2009).

In WP 5 I will evaluate the impact of the *BEST for Family* program on family health and service outcomes (e. g. quality of received support, family coping, grief intensity, quality of life) and furthermore explore their experiences with it, using a cross-sectional, mixed methods approach with family surveys (about 50-70 per site) and interviews (10-15 family members per site) 3-6 months after conclusion of *BEST for Family*.

Quantitative data from WP 4 and 5 will be analyzed descriptively using R. If the sample size permits, inferential statistics will be performed. Qualitative data will be analyzed with MAXQDA using a content analysis strategy. Quantitative and qualitative data will be analyzed separately, then merged compared-contrasted to explore commonalities and differences and will be presented together.

## Relevance for research and clinical practice

The *BEST for Family* project is highly relevant to research and clinical practice. First, it will adapt evidence-based knowledge to the specific context of the two specialized palliative care services using a participatory process. Second, the adopted program, which will be based on health promotion principles and be tailored to individual needs and risks for adverse outcomes, will be implemented and evaluated scientifically. Third, it will support families' ability to live with the loss and ensure early identification of those in need for specialist care.

From the researcher's point of view, the research project will systematically collect and synthesize the available evidence on which outcomes bereavement support for families has an impact on. This will make existing evidence more accessible for researchers, clinicians and policymakers. Furthermore, it will explore the perception and the experiences of bereaved families and health professionals with the support program and its implementation. It will expand the body of knowledge in the fields of family bereavement support in specialized palliative care and implementation science, hence closing existing knowledge gaps. The literature review will potentially inform the development of a Swiss clinical practice guideline on bereavement support in palliative care. The study findings will help to refine existing programs and services and support upscaling to other settings than specialized palliative care. Furthermore, the project will immediately help to improve clinical practice using implementation science methods to ensure sustainability of the program. Research team members are Prof. Dr. Rahel Naef (PI), Dr. Qëndresa Thaqi, Prof. Dr. David Blum, and Dr. Mirjam Buschor-Bichsel. The study is funded by the Gloria Grathwohl Palliativ-Stiftung.

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