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# An economic evaluation of an early palliative care intervention among patients with advanced cancer

Maud Maessen<sup>ab</sup>, Monica C. Fliedner<sup>b</sup>, Brigitta Gahl<sup>c</sup>, Marina Maier<sup>a</sup>, Daniel M. Aebersold<sup>d</sup>, Susanne Zwahlen<sup>e</sup>, Steffen Eychmüller<sup>ab</sup>

- <sup>a</sup> Institute of Social and Preventive Medicine, University of Bern, Switzerland
- <sup>b</sup> University Centre for Palliative Care, Inselspital, Bern University Hospital, University of Bern, Switzerland
- <sup>c</sup> CTU, University of Bern, Switzerland
- <sup>d</sup> Department of Radiation Oncology, Inselspital, Bern University Hospital, University of Bern, Switzerland
- <sup>e</sup> Unit for Specialised Palliative Care, Lindenhof Hospital, Bern, Switzerland

# **Summary**

BACKGROUND: Early integration of palliative care into oncology care has shown positive effects on patient symptoms and quality of life. It may also reduce health care costs. However given the heterogeneity of settings and interventions and the lack of information on the minimally effective dose for influencing care utilisation and costs, it remains uncertain whether early palliative care reduces costs

OBJECTIVES: We sought to determine whether an early palliative care intervention integrated in usual oncology care in a Swiss hospital setting reduced utilisation and costs of health care in the last month of life when compared with usual oncology care alone.

METHODS: We performed a cost-consequences analysis alongside a multicentre trial. We extracted costs from administrative health insurance data and health care utilisation from family caregiver surveys to compare two study arms: usual oncology care and usual oncology care plus the palliative care intervention. The intervention consisted of a single-structured, multiprofessional conversation with the patient about symptoms, end-of-life decisions, network building and support for carers (SENS). The early palliative care intervention was performed within 16 weeks of the diagnosis of a tumour stage not amenable or responsive to curative treatment.

RESULTS: We included 58 participants with advanced cancer in our economic evaluation study. Median overall health care costs in the last month of life were 7892 Swiss Francs (CHF) (interquartile range: CHF 5637–13,489) in the intervention arm and CHF 8492 [CHF 5411–12,012] in the control arm. The average total intervention treatment cost CHF 380 per patient. Integrating an early palliative care intervention into usual oncology care showed no significant difference in health care utilisation or overall health care costs between intervention and control arms (p = 0.98).

CONCLUSION: Although early palliative care is often presented as a cost-reducing care service, we could not show a significant effect of the SENS intervention on health care utilisation and costs in the last month of life. However, it may be that the intervention was not intensive enough, the timeframe too short or the study population too small for measurable effects. Patients appreciated the intervention. Single-structured early palliative care interventions are easy to implement in clinical practice and present low treatment costs. Further research about the economic impact of early palliative care should focus on extracting large, detailed cost databases showing potential shifts in cost and cost-effectiveness.

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# Introduction

# Early palliative care

Health care costs often increase at the end of life [1], especially those related to emergency admissions and hospital care [2]. To empower patients to decide autonomously about their life and care, their needs and support options should be identified early [3]. Early integration of palliative care into pathways of patients with severe, progressive, life-limiting illnesses, such as cancer, can support their autonomy and aims to maximise quality of life and family support. Randomised controlled trials (RCTs) and meta-analyses have confirmed the positive effects of early palliative care on symptoms, quality of life and care satisfaction among patients with advanced cancer [4, 5]. In addition, the American Society of Clinical Oncology and the European Society for Medical Oncology recommend early integration of palliative care services alongside usual oncology treatment [6, 7].

Studies on early integration of palliative care show decreased health care utilisation and health care costs [8–10]. However, details about types of health care utilisation and cost reductions vary between studies.

To understand how cost reductions can be reproduced in daily practice, it is therefore important to know what specific elements or parts of an early palliative care inter-

Maud Maessen University Center for Palliative Care Inselspital, University Hospital Bern SWAN C Freiburgstrasse 38 CH-3010 Bern

maud.maessen[at]insel.ch

vention programme cause reductions. Although reducing costs is not a goal of palliative care, palliative care interventions that reduce health costs are important for efforts to keep health care affordable and to allocate reimbursement to measures corresponding to patient goals. Palliative care interventions should be characterised as successful if healthcare costs match patient needs, expectations and preferences, not only if they reduce costs. To build excellent early palliative care services that also reduce unnecessary health care costs, health care managers require information about the kind and intensity level of every early palliative care service element and their effects on health care costs and on care utilisation.

# SENS intervention and SENS-economic objectives

The SENS trial was a multicentre RCT on SENS, an early palliative care intervention. SENS is a practice-orientated, thematic intervention structure for assessing, planning and evaluating the treatment of chronic progressive or potentially life-limiting diseases used at any stage requiring palliative support. The SENS trial examined the effects of a single, in-hospital conversational palliative care intervention among patients with advanced cancer. SENS topics include Symptoms, End-of-life decisions, Network building and Support for carers. Details of the SENS trial are published elsewhere [11, 12] (NCT01983956 on www.clinicaltrials.gov). Figure S1 in the appendix shows the SENS intervention structure.

The SENS intervention was performed within 16 weeks of diagnosis of a tumour stage not amenable or responsive to curative treatment. The SENS intervention is therefore defined as early palliative care. SENS helps uncover patients' needs and concerns from their perspective; set priorities; and organise support needed for patients and their families, while accommodating patients' wishes and values. The goal of SENS is to empower participants to find individual and optimal solutions for their specific needs and goals. Following the SENS-structured conversational intervention, we provided participants with specific questions to enhance further discussions with professionals [13, 14]. The intervention consisted of one single consultation with a senior palliative care physician and advanced practice nurse (APN); however, we allowed follow-up visits upon participant request (average 1.45 early specialist palliative care consultations). As a result of the SENS intervention, patients and their families understand and prepare for controlling symptoms and make relevant treatment and care decisions for redirecting care towards quality of life and function, which may eventually reduce emergency hospitalisations.

An additional study, SENS-economic, which placed no additional burden on SENS trial participants, collected and analysed information about costs and care utilisation within the SENS study. Potential cost-reducing effects of the SENS intervention are most likely highest at the end of life. For instance, when advance directives or anticipatory care planning for emergency situations lower the number of expensive health procedures, such as hospitalisations or diagnosis-specific treatment, no longer aligned with patient life goals. Therefore, we focused our cost analyses on the last month of life. The SENS-economic research question was: "Among participants with advanced cancer, is

early palliative care associated with reduced costs and utilisation of care when compared with usual oncology care at the end of life?". We hypothesised that the SENS intervention reduces costs.

However, if healthcare costs align with patient needs, expectations and preferences, palliative care interventions should be considered successful.

### Methods

# Study population

SENS trial participants were inpatients and outpatients with advanced cancer from the departments of medical and radiation oncology or internal medicine at University Hospital Bern, Inselspital, Switzerland. Participants were older than 18 years and had histologically confirmed advanced cancer no longer amenable to curative treatment. Cancer progression had been diagnosed at most 16 weeks before inclusion in the SENS trial. We included participants with good functional status [15]. Details of the study population are described elsewhere [11].

For the SENS-economic study, additional inclusion criteria required participants to have approved the use of their health insurance data in a separate clause in the informed consent and to have died by the end of the study. We considered eligible patients to be completely or partially lost to follow-up if we could not contact family caregivers, family caregivers did not reply or health insurance schemes refused to provide patient cost data. For pragmatic reasons, we began the SENS-economic study after the first 21 participants enrolled in the SENS trial.

# Control arm

Participants in the control arm received usual oncology care, i.e. without SENS-structured conversations, from oncologists with training in communication and tumour-centred care. Unlike patients in the intervention arm, they were treated primarily by oncologists without training in specialised palliative care. Outpatient consultations involved a systematic, structured oncology survey sheet providing information only about (a) drug therapy; (b) severity of major symptoms and physical examination; (c) imaging; and (d) laboratory diagnostics.

On request, a trained palliative care physician and APN performed specialist palliative care consultations. In addition, psycho-oncologists, social workers, pastoral workers and dietitians were available on demand, rather than actively offered to participants [11].

# Measurement of outcomes

We adopted the health insurance perspective in the SENSeconomic study and focused on health care service use and costs [16]. We followed our protocol to collect health care data about participants during the last month of life from two sources: (1) questionnaires about health utilisation filled out by family caregivers after participants had died and (2) medical cost data derived from patient compulsory basic health insurance administrative information. Details of our data collection process are given in table S1 in the appendix.

# Family caregiver questionnaire

Three months after each participant's death, we invited family caregivers by mail or phone to complete questionnaires about health care utilisation during the participant's last month of life. The study nurse mailed family caregivers study information forms and questionnaires about health care utilisation. Family caregiver questionnaires included questions about caregiver characteristics, place where the participant died, specialisations of treating physicians and health care utilisation during the last month of life, including number of general practitioner (GP) and specialist visits, hospital admissions, emergency consultations and calls to emergency numbers, nursing home care and home care services by district nurses/mobile palliative care teams.

# Health care insurance costs

Our health insurance data only includes costs eligible for reimbursement as per Swiss basic health insurance guidelines. Health insurance is compulsory for all permanent inhabitants of Switzerland. It includes health care costs, such as hospitalisation, medications and ambulatory care. Only costs reported to health insurance schemes could be analysed.

We included only costs accumulated in the last month of life. Some health care treatments started more than one month before the participant died and continued until the participant's death. In these situations, we were unable to extract health care costs generated only in the last month of life from our health insurance data because only the total cost of these services was provided. Therefore, in our analyses we included only health care costs in proportion to the time these services were performed in the last month before death. We based cost types on health insurance data labeling and information. We categorised costs reported as GP services to health insurance schemes in communities and hospitals as outpatient physician care – a category also including outpatient care from other specialist physicians.

# Other outcomes

We extracted data from SENS trial questionnaires, such as health service use, Palliative Outcome Scale [17], Functional Assessment of Cancer Therapy – General [18] and Lubben Social Network Scale [19] from the last follow-up time point before participant death.

We calculated intervention treatment costs by using the total time needed for each intervention and its resources. We only included costs directly related to the intervention, such as information leaflets, since those costs would also apply when integrating the intervention into usual care. We excluded variable study-related costs, such as screening eligible patients or helping participants complete study questionnaires, but included variable intervention-related costs for renting the hospital consultation room. Average total costs included variable personnel costs for a senior palliative care physician and APN and costs for materials and hospital consultation room rent. Material costs only included leaflets given to participants.

### Statistical analysis and characterisation of uncertainty

According to the null hypothesis, change in total health care costs is the same among participants who received the SENS intervention alongside usual oncology care and those who received usual oncology care alone. We tested our null hypothesis against a two-tailed alternative, providing 95% confidence intervals (CI) for all reported effect measures and using two-tailed p values.

We represented continuous data as mean  $\pm$  standard deviation (SD) and median (interquartile range [IQR]) because some variables are zero-inflated, so the median (IQR) does not provide a meaningful overview. Mean and SD, although certainly not perfect, at least allow rudimentary comparison. We compared groups using the Wilcoxon-Mann-Whitney test. We presented categorical variables as number (%) and compared them using Fisher's exact test. To increase comparability between the studies, we based our analysis on the intention-to-treat principle, as previously done in another published SENS trial study [11].

We analysed all randomised participants and their clusters according to randomised assignment regardless of treatment. As a sensitivity analysis to better understand the cost, we also performed per-protocol analyses.

We performed all analyses using Stata 16 (Stata Corp, College Station, Texas, USA).

### Ethical approval

The cantonal ethics committee of Bern, Switzerland approved the study (KEK number: 102/13, 29-05-2017). The study protocol is registered with the Swiss ethical committee (102/2013).

# Results

# Characteristics of participants

According to inclusion and exclusion criteria, 58 of 150 participants with advanced cancer included in the SENS trial were eligible for the SENS-economic study. Of these 58 participants eligible for the SENS-economic study, matching family caregivers provided surveys. Figure 1 shows the CONSORT inclusion flow diagram.

Participants in the intervention and control arms included in the SENS-economic study showed similar characteristics at baseline and at the last follow-up measurement of the SENS trial (table 1).

The average time between the last follow-up measurement in the SENS trial and death was 168 days in the intervention arm and 144 days in the control arm (p = 0.93). There were no significant differences in this follow-up time point for any reported outcome between study arms. We show characteristics between study arms, which were similar, in our display of characteristics of family caregivers and patients who answered the family caregiver questionnaire (tables 2 and 3 in the appendix).

# Health care cost

On average, participants in the intervention arm had CHF 600 lower absolute overall health care costs in the last month of life when compared with participants in the usual care arm (p = 0.98) (table 2). Costs for inpatient care were

the highest cost subcategory. In both study arms, inpatient costs were higher than all outpatient cost types together. No cost type showed a significant difference between the two study arms.

Total health care costs decreased with increasing age in both arms (figure 2).

In the appendix (table S4), we show similar results from the per-protocol analyses of the costs, excluding three participants who did not receive the SENS intervention according to study protocol. In per-protocol analyses, the intervention arm showed CHF 1204 lower absolute overall health care costs in the last month of life when compared with the control arm (p = 0.66).

# Treatment costs and duration of intervention

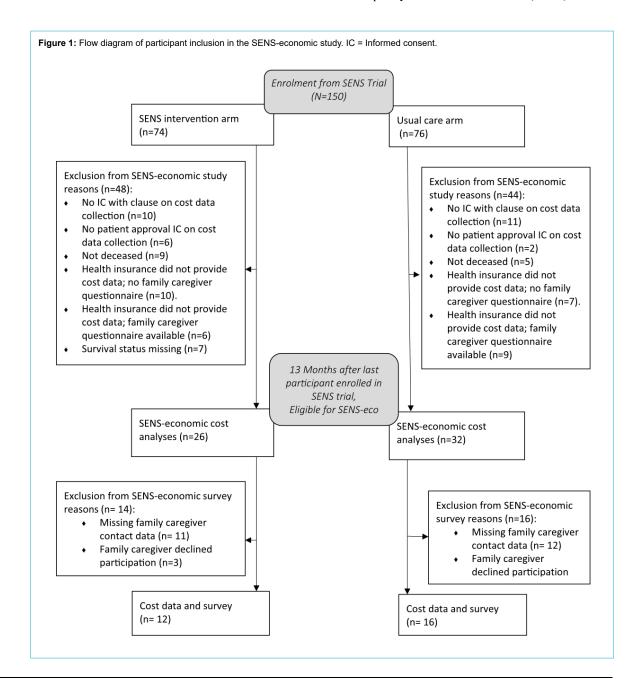
The total average cost of the SENS intervention was CHF 380 per participant. The average time of intervention consultations (one or more consultations) for participants was

52 min (range: 5–170). In table S5 in the appendix, we provide cost details.

### Health care utilisation

Health care utilisation analyses showed no significant differences between the intervention and control arm at the last SENS trial follow-up measurement (table 1) and in the last month of life (table 3). Although not significant, descriptive data showed family caregivers of participants in the intervention arm reported fewer deaths in hospital (42% vs 56%), lower use of hospital emergency departments (25% vs 44%), lower non-use of nursing home care (42% vs 56%), higher rate of outpatient visits by specialists (50% vs 31%) and lower rate of outpatient visits by GPs (42% vs 50%) when compared with participants in the control arm (table 3).

In the last month of life, most participants in both arms renounced medical care and support (table 3). Participants most frequently declined "Resuscitation" (n = 10) followed



by "Continuation with radiation therapy, chemotherapy or hormone therapies" (n = 8), "Starting new radiation therapy, chemotherapy or hormone therapies" (n = 7) or "Receiving artificial nutrition" (n = 7) (table S6 in the appendix).

Table 1:

Baseline and follow-up characteristics of 58 participants with advanced cancer. Outcomes are expressed as median (interquartile range), mean ± standard deviation or n (%).

		Total (n = 58)	SENS (n = 26)	Control (n = 32)	p value
Baseline meas	urements				
Age (years)		67 (60–75)	66 (59–74)	68 (62–75)	0.24
Female sex		18 (31%)	8 (31%)	10 (31%)	1.00
Marital status					0.07
Single		5 (8.6%)	2 (7.7%)	3 (9.4%)	
Married		37 (64%)	14 (54%)	23 (72%)	
Widowed	d	5 (8.6%)	5 (19%)	0 (0.00%)	
Divorced		11 (19%)	5 (19%)	6 (19%)	
Religion					0.53
Catholic		15 (26%)	6 (23%)	9 (28%)	
Protesta	nt	33 (57%)	15 (58%)	18 (56%)	
None		8 (14%)	5 (19%)	3 (9.4%)	
Other		2 (3.4%)	0 (0%)	2 (6.3%)	
Availability of a	dvance directive				0.72
No		20 (34%)	8 (31%)	12 (38%)	
Yes		5 (8.6%)	3 (12%)	2 (6.3%)	
Unknowr	า	33 (57%)	15 (58%)	18 (56%)	
Cancer entity					0.94
Lung car	ncer	20 (34%)	8 (31%)	12 (38%)	
Colorecta	al cancer	4 (6.9%)	2 (7.7%)	2 (6.3%)	
Prostate	cancer	5 (8.6%)	3 (12%)	2 (6.3%)	
Breast ca	ancer	4 (6.9%)	2 (7.7%)	2 (6.3%)	
Urothelia	ıl cancer	3 (5.2%)	2 (7.7%)	1 (3.1%)	
Pancreat	tic cancer	22 (38%)	9 (35%)	13 (41%)	
ECOG PS					0.25
0		18 (31%)	11 (42%)	7 (22%)	
1		28 (48%)	10 (38%)	18 (56%)	
2		12 (21%)	5 (19%)	7 (22%)	
Comorbidities		52 (90%)	23 (88%)	29 (91%)	1.00
Last questionn	aire in SENS trial patient follow-up				·
Physician visit		36 (62%)	18 (69%)	18 (56%)	0.42
Hospital emerg	gency room visit	17 (29%)	6 (23%)	11 (34%)	0.40
Hospital overni	ight stay	16 (28%)	6 (23%)	10 (31%)	0.56
FACT-G		54 (50–60)	53 (51–55)	56 (50–62)	0.56
POS		9.0 (6.0–13)	8.0 (6.0–14)	9.0 (7.0–12)	0.69
LSNS-6		19 (15–23)	17 (14–23)	20 (17–23)	0.36
NCCN distress	thermometer	4.0 (2.0-5.5)	4.0 (2.0-5.0)	4.0 (2.0-6.0)	0.52

ECOG PS: Eastern Cooperative Oncology Group Performance Status; NCCN: National Comprehensive Cancer Network; FACT-G: Functional Assessment of Cancer Therapy—General scale; POS: Palliative care Outcome Scale; LSNS-6: abbreviated Lubben Social Network Score.

Table 2:
Compulsory Swiss basic health insurance eligible care costs of 58 participants in the last month of life in Swiss Francs (CHF). Outcomes are expressed as median (interquartile range).

Cost type	Total (n = 58)	SENS (n = 26)	Control (n = 32)	p Value
Total health care costs	7985 (5637–12450)	7892 (5637–13489)	8492 (5411–12012)	0.98
Inpatient care	5974 (0–10970)	6214 (3257–10970)	3848 (0–10614)	0.50
Outpatient physician care	556 (46–1386)	498 (16–1342)	691 (220–1706)	0.36
Outpatient nursing care	243 (0–950)	3.3 (0–808)	336 (0–1323)	0.17
Outpatient laboratory	0 (0–79)	0 (0–92)	0 (0–62)	0.12
Outpatient medications	316 (50–607)	125 (0–670)	389 (119–584)	0.28
Outpatient care products	0 (0–232)	0 (0–124)	1.4 (0–369)	0.18
Transportation	0.00 (0.00–0.00)	0.00 (0.00-0.00)	0.00 (0.00–19)	0.27
Outpatient health professionals*	0.00 (0.00–0.00)	0.00 (0.00–0.00)	0.00 (0.00–0.00)	0.23
Other care	0.00 (0.00–0.00)	0.00 (0.00–0.00)	0.00 (0.00–0.00)	0.78

<sup>\*</sup> Excluding physician and nurses.

# Discussion

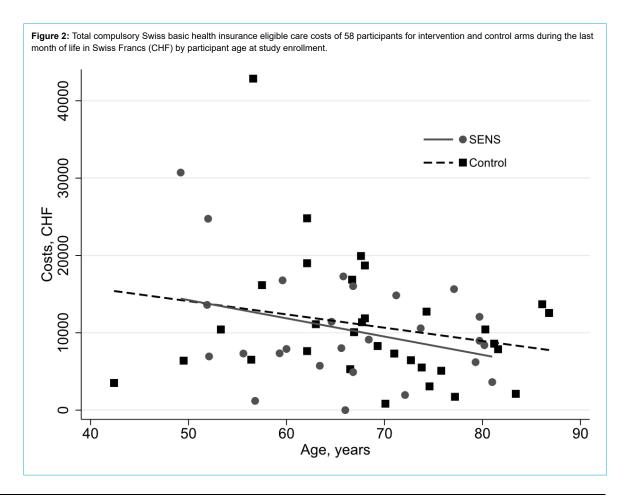
# Study findings

Our results showed no significant differences in health care utilisation or overall costs for participants with cancer who received the SENS intervention alongside usual oncology care and those who received usual oncology care alone. In both study arms, inpatient costs generated most health care costs in the last month of life. In concordance with these results, descriptive analyses showed that participants in the intervention arm used less hospital care and died more often at home. When compared with the control arm, the average reduction of overall health care costs in the intervention arm outweighed the costs of the SENS intervention.

The literature on effects of early palliative care on health care costs has contradictory results. Comparing study results is challenging since study methods, timing, health care systems and content of early palliative care interventions are heterogeneous. A Swiss study using administrative hospital data of deceased patients instead of health insurance data showed similar results [20]. Their overall hospital cost analyses of the final hospitalisation before death showed no significant cost reduction for patients receiving specialist palliative care compared with those receiving usual care. The study was not specifically about early palliative care, which complicates comparison of cost results because timing influences care costs [21]. However, detailed analyses showed that among palliative care populations, average daily hospital costs significantly decreased CHF -3224 (95% CI: -3811 - -2631). The data showed a shift in type of costs after specialist palliative care. Deceased patients who received in-hospital specialist palliative care showed fewer costs for diagnostic interventions and medications when compared with participants receiving no specialist palliative care; however, participants receiving specialist palliative care demonstrated higher costs for catering, rooms, nursing care, social counselling and nonmedical therapists [20]. Our study method disallowed analysis of potential shifts between medical care and comfort care costs. However, our study demonstrates that our inpatient SENS intervention showed no negative effect on increasing costs in the outpatient setting.

Heterogeneity was also displayed in a study of 12 Dutch hospitals, which reported no significant differences in total mean inpatient costs [22]. The intervention was similar to our SENS structure, assessing patient symptoms and physical, emotional, social and spiritual problems and coordination of care. In addition, the health care systems of both counties are similar. However, the Dutch study defined early palliative care as a palliative care consultation within three days of hospital admission, which could be at a later time point than our early palliative care consultation, which was within 16 weeks of the diagnosis of advanced cancer no longer amenable to curative treatment. The Dutch study also used 3-month follow-up data, including participants who survived during this period, which indicates a higher variety of disease stages compared with our study, focusing on the last month of life only. These differences possibly influence health care costs [23, 24].

Our study confirmed a trend in the literature showing older participants with lower health care costs than younger participants at end of life [25, 26]. Our study results contradict



studies showing significant reductions in health care costs related to early palliative care among patients with cancer [23, 27, 28]; yet again, these are studies with heterogeneous study methods and interventions. A meta-analysis showed total direct hospital costs decreased with hospital palliative care consultation within 3 days of hospital admission among patients with cancer (-4251 USD; 95% CI -4664 - 3837 USD; p <0.001) [23]. A cohort study reported a cost reduction derived mainly from shorter hospital stays [28]. Since available literature focused on inpatient health care costs mostly for single hospital admissions, it is unclear whether patients generated more health care costs in outpatient sectors, during later hospital admissions or from out-of-pocket payments for patients/ families. In these studies, early palliative care was mostly defined by the number of days after hospital admission, such as fewer than three days, when palliative care consultations occurred, not by disease stage. Such differences make it difficult to compare results. Our study defined early palliative care based on time since diagnosis of a lifelimiting cancer disease and included outpatient costs - a setting where cost savings are more difficult to measure [29].

Even though the expected effect on inpatient costs is higher than outpatient costs and inpatient cost data are often better available, future economic analyses of palliative care should not focus on inpatient settings only.

Outpatient analyses are important for future palliative care. If patients have fewer (expensive) inpatient days, the need for information on excellent, affordable alternatives in outpatient care is of high relevance. Finally, use of hospital care during the last weeks of life – including length of stay and costs – remains a complex outcome and possibly reflects reimbursement incentives within the Swiss health care system. With outpatient and long-term care demands, a high proportion of out-of-pocket expenses and affordable care solutions might not always be immediately available; whereas hospital costs are mostly covered by health insurance in Switzerland. Thus, patients and family carers in Switzerland and elsewhere possibly prefer (expensive) hospital care because of such regulations.

# Strengths and limitations

Since RCT design decreases bias between two study arms, our study design is a strength. The clarity of our intervention is also a strength because treatment costs are more

**Table 3:**Health care utilisation reported in family caregiver questionnaire of participants included in cost analyses.

	SENS (n =12)	Control (n = 16)	p value
Place of participant's death			0.56
Home	5 (42%)	3 (19%)	
Nursing home	0 (0.0%)	2 (13%)	
Hospital	5 (42%)	9 (56%)	
Other	2 (17%)	2 (13%)	
Specialisation of treating physician			1.00
General Practitioner	3 (25%)	4 (25%)	
Oncologist	6 (50%)	9 (56%)	
Palliative care specialist	1 (8.3%)	1 (6.3%)	
Unknown	1 (8.3%)	1 (6.3%)	
Other	1 (8.3%)	1 (6.3%)	
Missing data	3 (25%)	4 (25%)	
risited hospital emergency room?			0.42
No	8 (67%)	8 (50%)	
Yes	3 (25%)	7 (44%)	
Missing data	1 (8.3%)	0 (0.0%)	
Unknown	0 (0.0%)	1 (6.3%)	
Stayed at least one night in hospital?			1.00
No	3 (25%)	4 (25%)	
Yes	9 (75%)	12(75%)	
Jsed nursing home care?			0.75
No	5 (42%)	9 (56%)	
Yes, fewer than once per day	0 (0.0%)	1 (6.3%)	
Yes, once per day	4 (33%)	3 (19%)	
Yes, twice per day	2 (17%)	3 (19%)	
Yes, three times per day	1 (8.3%)	0 (0.0%)	
Stayed in retirement home or nursing home?			0.49
No	12 (100%)	14 (88%)	
Yes	0 (0.0%)	2 (13%)	
Renounced medical care or support?			0.90
No	4 (33%)	5 (31%)	
Yes	7 (58%)	10 (63%)	
Missing data	0 (0.0%)	1 (6.3%)	
Unknown	1 (8.3%)	0 (0.0%)	
Outpatient medical specialist visits with medical practice outside or inside hospital	6 (50%)	5 (31%)	0.44
Outpatient general practitioner visits with medical practice inside or outside hospital	5 (42%)	8 (50%)	0.72

transparent when compared with integrated, comprehensive palliative care intervention programmes. As another strength, the single structured conversational intervention allowed us to study a systematic, step-wise increase in intensity of specialist palliative care and to determine the effects of each added intervention element. We conducted our study directly alongside the RCT before results of the studied intervention were available; therefore, the added analysis maximises use of data. Furthermore, results from economic analyses simplify decisions when planning next research steps for an intervention and possible implementation into usual (oncology) care [30].

A small sample size is the most important limitation; it decreases the robustness of our results. Since cost data provision required approval by 16 different health insurance schemes and each provided their own database characteristics, challenges led to missing or loss of data details. A complete, accessible national database on health care costs for research decreases missing cost data, yet does not exist. Other countries possibly desire a national health care database including costs; our study illustrates that missing health care cost data limit analyses.

Given that we excluded participants after randomisation for not meeting additional inclusion criteria and encountered missing data, (unobserved) bias was possibly introduced. Another limitation involves unrepresented national languages and geographical regions, decreasing result generalisability. Studies have shown that health care utilisation and costs vary between geographic, language and hospital regions [31-33]. Knowledge and attitudes about palliative care also vary between Swiss language regions. A survey of the Swiss government showed that the general population in German-speaking regions of Switzerland more often reported having advance directives (19%) when compared with French-speaking (9%) and Italian-speaking (7%) regions [34]. However, in German-speaking regions, 55% reported knowing the term "palliative care" compared with 73% in French-speaking and 64% in Italian-speaking regions [34]. Such findings possibly indicate that our German-language region study population is more ideal since they seemed willing to define advance directives early – a part of the SENS intervention.

Also, they were less aware of palliative care services, with participants in the control arm less likely to request it. Another limitation involves allowing control arm participants to request palliative care services. The SENS trial showed this to be a relevant yet small effect [11].

Focusing our analyses on the last month of life makes the study population more heterogeneous and clear about short life expectancy and disease stage, which increases the probability that patients decide to prioritise their personal end-of-life goals over another hospitalisation or intensive treatment. However, the short time period also prevented us from providing any information about an earlier effect from the intervention; an earlier effect is especially important since studies have clearly shown reduced hospital costs immediately following palliative care interventions [23]

The health service payer perspective is another limitation. As a result, our data cannot determine whether health care costs shifted from health service payers to participants and families as out-of-pocket expenses. Revealing a fuller pic-

ture of interventions causing cost reductions and potential shifts in health care costs requires more detailed health care data about inpatient and outpatient care and studies with higher statistical power.

# Implications for practice

The SENS trial included three studies. The quantitative study showed that the single SENS intervention did not decrease distress nor improve quality of life among participants with cancer [11, 12]. Yet, the nested interview study (12) showed that participants experienced the SENS intervention as beneficial and felt it should be incorporated into routine oncology care. Lastly, the present study showed the relatively low costs for the intervention; however, we did not identify any significant difference in health care costs between the intervention and control arms. Following the hierarchy of evidence, health care managers should cautiously evaluate implementing our intervention into usual care because primary outcomes - costs and participant distress - did not statistically improve. Nevertheless, instead of providing no early palliative care at all, we advise the implementation of an early palliative care intervention based on SENS and in a repeated format, thus giving more weight to individual patient voices. A permanent evaluation determining whether the allocation of costs at end of life corresponds to individual patient goals is necessary. Since participants valued the intervention (12), treatment costs were low with no negative effects, such as increased distress. As a health care cost-reducing measure, care managers should evaluate integrated and more intensive early palliative care interventions.

# Conclusion

Although integrating an early palliative care intervention into usual oncology care showed no significant statistical differences in health care utilisation or overall health care costs between the intervention and control arm among participants with cancer, integrating such an intervention is beneficial to individuals. However, a small sample size reduces the robustness of this conclusion. We recommend further economic research on early palliative care focusing on extracting large, detailed cost databases showing potential shifts in cost and cost effectiveness.

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Author contributions: S. Zwahlen, S. Eychmüller, M. Maessen and D. M. Aebersold designed the study. M. Maessen, M. Maier and M. C. Fliedner collected the data. B. Gahl and M. Maessen performed the analysis and designed the figures. M. Maessen drafted the manuscript. S. Exchmüller, M. Maessen, M. Maier, B. Gahl, M. C. Fliedner, S. Zwahlen and D. M. Aebersold critically reviewed the manuscript. All authors discussed the results and commented on the manuscript. M. Maessen is responsible for the overall content of the manuscript.

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### Potential competing interests

All authors have completed and submitted the International Committee of Medical Journal Editors form for disclosure of potential conflicts of interest. No potential conflict of interest related to the content of this manuscript was disclosed.

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# Appendix: supplementary tables and figure

# Table S1:

Overview of the data collection process showing time points of data collection, differentiating between questionnaires of SENS and SENS-economic studies and intervention start point.

Study	SENS	SENS			
Time points of data collation	Month 0 (Baseline)	Month 2	Month 4	Month 6	After death
SENS intervention	no	yes*	yes*	yes*	yes*
SENS questionnaire for patients	yes	yes	yes	yes	no
SENS-economic: health insurance data from last month of life	no	no	no	no	yes
SENS-economic questionnaire for family caregivers	no	no	no	no	yes

<sup>\*</sup>The SENS intervention is integrated into usual oncology care and consists of a single specialist palliative care consultation. Further specialist palliative care consultations were provided if needed.

## Table S2:

Characteristics of 28 family caregivers who answered the family caregivers' questionnaire.

Data from family caregiver survey	<b>SENS</b> (n = 12)	Control (n = 16)	p value
Relationship to patient			1.0
Partner	9 (75%)	11 (69%)	
Child	1 (8.3%)	2 (13%)	
Brother / sister	0 (0.0%)	1 (6.3%)	
Other	2 (17%)	2 (13%)	
Age	62 (11)	64 (9.0)	0.75
Female sex	11 (92%)	9 (56%)	0.09

Table S3:
Baseline and follow-up characteristics of a subgroup of 28 patients with advanced cancer with family caregivers who answered family caregivers' questionnaire. Outcomes are expressed as median (interquartile range), mean ± standard deviation or n (%).

	Total (n = 28)	SENS (n = 12)	Standard (n = 16)	P value
Baseline measurements				
Age (years)	67 (62–73)	67 (58–73)	67 (62–73)	0.75
Female sex	9 (32%)	3 (25%)	6 (38%)	0.69
Marital Status				0.63
Single	4 (14%)	1 (8.3%)	3 (19%)	
Married	17 (61%)	8 (67%)	9 (56%)	
Widowed	1 (3.6%)	1 (8.3%)	0 (0.00%)	
Divorced	6 (21%)	2 (17%)	4 (25%)	
Religion				0.84
Catholic	6 (21%)	2 (17%)	4 (25%)	
Protestant	18 (64%)	8 (67%)	10 (63%)	
None	3 (11%)	2 (17%)	1 (6.3%)	
Other	1 (3.6%)	0 (0.00%)	1 (6.3%)	
Availability of an advance directive				0.81
No	7 (25%)	3 (25%)	4 (25%)	
Yes	1 (3.6%)	1 (8.3%)	0 (0.00%)	
Unknown	20 (71%)	8 (67%)	12 (75%)	
Cancer diagnosis				0.60
Lung cancer	11 (39%)	5 (42%)	6 (38%)	
Colorectal cancer	2 (7.1%)	1 (8.3%)	1 (6.3%)	
Prostate cancer	2 (7.1%)	1 (8.3%)	1 (6.3%)	
Breast cancer	1 (3.6%)	1 (8.3%)	0 (0.00%)	
Urothelial cancer	3 (11%)	2 (17%)	1 (6.3%)	
Pancreatic cancer	9 (32%)	2 (17%)	7 (44%)	
ECOG PS				1.00
0	6 (21%)	3 (25%)	3 (19%)	
1	17 (61%)	7 (58%)	10 (63%)	
2	5 (18%)	2 (17%)	3 (19%)	
Comorbidities	25 (89%)	11 (92%)	14 (88%)	1.00
Last questionnaire in patient follow-up	1	1		
Physician visit	20 (71%)	8 (67%)	12 (75%)	0.69
Hospital emergency room visit	8 (29%)	1 (8.3%)	7 (44%)	0.09
Hospital overnight stay	8 (29%)	2 (17%)	6 (38%)	0.40
FACT-G	56 (52–62)	53 (52–56)	61 (51–63)	0.44
POS	10 (7.0–14)	8.5 (6.0–14)	10 (7.0–14)	0.43
LSNS-6	21 (16–24)	17 (14–24)	22 (19–25)	0.12
NCCN distress thermometer	4.0 (2.0–5.0)	4.0 (2.5–5.5)	4.0 (2.0–5.0)	1.00

ECOG PS: Eastern Cooperative Oncology Group Performance Status; NCCN: National Comprehensive Cancer Network; FACT-G: Functional Assessment of Cancer Therapy – General scale; POS: Palliative care Outcome Scale; LSNS-6: abbreviated Lubben Social Network Score.

**Table S4:**Per-protocol analysis of costs in Swiss Francs (CHF); three participants in the study population did not receive the SENS intervention according to protocol.

	Total (n = 55)	SENS (n = 23)	Control (n = 32)	р
Total health care costs	7632 (5214–12367)	7288 (5214–12367)	8492 (5411–12012)	0.66
Outpatient physician care	580 (59–1386)	512 (27–1342)	691 (220–1706)	0.48
Outpatient nursing care	270 (0.00–1037)	0.00 (0.00-808)	336 (0.00–1323)	0.19
Outpatient laboratory	0.00 (0.00–79)	0.00 (0.00–92)	0.00 (0.00–62)	0.17
Outpatient medication	386 (62–620)	275 (18–843)	389 (119–584)	0.64
Outpatient care products	0.00 (0.00–232)	0.00 (0.00-124)	1.4 (0.00–369)	0.54
Transport	0.00 (0.00-0.00)	0.00 (0.00-0.00)	0.00 (0.00–19)	0.20
Outpatient health professionals (excluding physicians and nurses)	0.00 (0.00-0.00)	0.00 (0.00-0.00)	0.00 (0.00-0.00)	0.29
Other care	0.00 (0.00-0.00)	0.00 (0.00-0.00)	0.00 (0.00-0.00)	0.96
Inpatient	4010 (0.00–9602)	5833 (0.00–9123)	3848 (0.00–10614)	0.79

Table S5:

Overview of intervention treatment costs in Swiss Francs (CHF).

Cost type	Average consultation time in minutes	Administrative time in minutes	Costs* (CHF)	Total costs (CHF)	
Specialist palliative care physician	52	20	192	230.4	
Advanced practice nurse	52	20	96	115.2	
3 leaflets (design and print)	-	-	10.5	10.5	
Consultation room rent (1 hour)	-	-	24.3	24.3	
Total					

<sup>\*</sup> Provided by hospital administration in matching year.

# Table S6:

Overview of health care that participants declined according to family caregivers.

Care type declined by patient*	SENS (n = 12)	Control (n = 16)
Resuscitation in the event of cardiovascular arrest	6 (50%)	4 (25%)
Continuation of radiation therapy, chemotherapy or hormone therapy	3 (25%)	5 (31%)
Starting new radiation therapy, chemotherapy or hormone therapy	3 (25%)	4 (25%)
Enteral nutrition	3 (25%)	4 (25%)
Surgery	2 (17%)	3 (19%)
Continuation of medication	2 (17%)	3 (19%)
Starting new medication	2 (17%)	2 (13%)
Special examinations (such as PET or blood tests)	2 (17%)	2 (13%)
Parenteral nutrition	1 (8.3%)	1 (6.3%)
(More) specialist palliative nursing home care	1 (8.3%)	1 (6.3%)
(More) nursing home care	0 (0.0%)	1 (6.3%)
Planned hospitalisation	0 (0.0%)	1 (6.3%)
Emergency hospitalisation	0 (0.0%)	1 (6.3%)
Blood transfusions	1 (8.3%)	0 (0.0%)
Other	1 (8.3%)	2 (13%)
Total	27	32

PET: Positron Emission Tomography.

<sup>\*</sup>Multiple answers per family caregiver are possible.

Figure S1: SENS structure as provided on a summary pocket card.

# Worksheet for patients and families

Based on the SENS structure, a worksheet (also called "prompt sheet") was developed for patients and their relatives. It can be used as a checklist, for preparing roundtable discussions or for concrete planning. The structure can also serve as a basis for discussions regarding a living will.

### Application of SENS in practice

- Assessment at the beginning of palliative care and treatment or as a follow-up
- As a tool to prepare a 'round table' and discussions about the needs and limitations, but also about resources of patients and relatives.
- As a tool for the creation of a care plan and coordination of the care network (for relatives as well as professionals)
- As a structure for documenting the basic palliative assessment, including billing to third parties (including health insurance companies)
- ✓ A grid for case discussions and teaching

For more information about proactive care planning go to www.iplan-care.ch:





### SENS® Pocket Card

SENS is a person-centered structure for the assessment of distressing symptoms/factors and therapy planning in people with chronically progressive and/or life-limiting diseases. The aim is to find a common language for the concrete planning of therapeutic and supportive measures while naming the achievable goals. The topics and contents were defined based on many years of evaluation with patients and their relatives.

### **SENS** stands for

S ymptom management
E nd of life decisions / expectations
N etwork - organization
S upport for the carers

SENS is recognized as a tool for palliative care assessment. It can and should be supplemented by more in-depth assessments in the subject area of symptoms. Two questions are central in parallel: 'what is the patient suffering from' in the medical sense, and: 'who is this person?

# SENS©: Problem areas and resources

Assess in general: General well-being, current problem areas, resources and coping strategies of patient and relatives

# S ymptoms and Symptom Management

Physical symptoms	Pain, nausea, dyspnea, exhaustion/fatigue, appetite, digestion, pruritus, edema
Psychological symptoms	Deterioration of cognition, anxiety depression, demoralization incl. death wish, sleep disturbance.
Social stressors	Effects on relationships and social activities, hobbies, occupation, and finances.

# E nd of life decisions/ Expectations

Personal history and values	Previous life contents (family, job), values, quality of life
Spiritual/ cultural Needs	Belonging to faith/spiritual community, dealing with questions of meaning
Expectations and patient goals	Most important goals and wishes Realistic? Measurand (function)?
Medical and nursing decisions	Current medical situation/ planned therapies, existing policy decisions (CPR, intubation, emergency plan); current capacity for judgment Representative for medical decisions
End of life planning	"Unfinished business", will, wishes regarding place of death, rituals, burial

### N etwork - organization

Living conditions	Current housing situation (stairs etc?), alternatives, aids, cohabitants, application AUF/IV
Private network	Relatives, friends, volunteers, etc., availabilities?
Professional network + availability	Family doctor (home visits?), Spitex. mobile palliative service, social work, psychological support, pastoral care; emergency button, rescue chain?

# S upport for the caregivers

Important: record what is bothering the patient!

Load and Relief options for relatives/friends	Existing or necessary: - Care support - General care (e.g. night watch, housekeeping) - Psychological support
Financial stressors for family members	Possibilities of being released from work? Financial bottlenecks in the future?

# More information

www.sens-plan.com or palliativzentrum@insel.ch

University Center for Palliative Care, Inselspital, University Hospital Bern, Switzerland

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