

# Palliative home care for patients with advanced haematological malignancies—a multicenter survey

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**Abstract** Patients with advanced haematological malignancies in non-curative settings suffer from complex physical symptoms and psychosocial distress, comparable to patients with solid tumour entities. Nevertheless, numerous problems at the interface between haematology and palliative home care have been described. From January 2011 until October 2014, we performed a retrospective, multicenter analysis of all patients with haematological malignancies (ICD 10: C81–C95) being treated by the respective specialized palliative home care (SAPV) team. Three SAPV teams were surveyed. Disease entity, physical symptoms, psychosocial distress, number of hospital admissions, therapeutic interventions and other items were analysed descriptively. Of 3,955 SAPV patients, 1.8% ( $n = 73$ ) suffered from haematological malignancies. Main problems were deterioration of general condition, pain or psychological problems. Thirty-seven percent developed new symptoms during SAPV, mainly pain, psychological distress or deterioration of general status. In 33%, patients were referred to hospital, mainly due to deterioration of general condition or pain. Seventy percent died within 3 months after beginning SAPV care; 83% died at home or in a nursing home. Patients suffering from advanced haematological malignancies were statistically underrepresented in SAPV, and SAPV was installed rather at the very last days of life. By

far, more patients were able to die outside a hospital as compared to reference cohorts of haematological patients not being treated in SAPV. The spectrum of documented problems is comparable to other patient cohorts being treated in SAPV; therefore, the options and benefits of palliative home care should be incorporated in palliative haematological treatment concepts more vigorously and consequently.

**Keywords** Specialized palliative home care · Haematological malignancies · Physical symptoms · Psychosocial distress

## Introduction

Patients with haematological malignancies (as defined by ICD 10: C81–C95) in advanced, incurable stages suffer from a numerous symptoms [1]. Pain, bleeding complications, anaemia, fatigue, stomatitis, depression and an increased risk for local and systemic infections, including septic shock, were found to be leading problems [2–7]. Currently, those patients are mostly being treated as inpatients in specialized haematological institutions, and the cooperation with specialized palliative care structures has been described as being insufficient [8–11]. Accordingly, the German Hospice and Palliative Care Evaluation (HOPE) documented that only 5.1% of all registered patients (mainly patients from palliative care units and inpatient hospices) suffered from a haematological malignancies [12], although age adjusted mortality would suggest a much higher proportion [13]. A number of publications confirm this patient group being underrepresented in SAPV [8, 14, 15]. Further, patients suffering from haematological disease received aggressive therapy even in far advanced and prognostically unfavourable situations (e.g. ICU referral, chemotherapy, complex anti-infective interventions)—more than patients suffering from solid cancer entities [3, 5, 9, 10].

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This discrepancy might be related to a more general symptom spectrum in (systemic) haematological disease, as opposed to “classical” focal symptoms in palliative care, like focal pain or compressive symptoms in metastatic solid tumours [9, 10]. Therefore, the specific demands of haematological patients might be missed when assessing the patient with a “standard” palliative care approach. From a haematology perspective, the long-lasting therapeutic relationship between haematologist and his/her patient, and prognostication issues (when is “palliative?”), has been discussed to contribute to the reluctance to involve specialized palliative care structures [8]. A single center study also described differences in the general therapeutic attitude between haematology specialists and oncology specialists [16], leading to differences in referral behaviour. Other reasons for delayed referral, as described by Cheng et al. and Cheng, may be a long-standing curative therapy aim, frequent episodes of intensive care or the rapid and unpredictable progress [5, 17].

First steps have been undertaken to better incorporate palliative care structures into the therapeutic concept for patients with advanced haematological disease (as demanded in literature [18]). Corbett [19] and Niscola [6, 7], for instance, documented an increasing number of patients with haematological malignancies in their palliative care institutions—outpatient and inpatient. This was found to be associated with positive influences on several outcome parameters [19, 20]. Attempts were made to care for patients with haematological disease *at home* (comparable to palliative home care for patients with solid cancer entities). Conceptual feasibility was demonstrated also when specific haematological problems like pain or bleeding occurred, including the transfusion of blood products [2, 4, 7, 21], so that hospital (re-)admissions could be avoided.

A systematic assessment and analysis of physical symptoms and psychosocial demands of patients with advanced haematological disease, being treated in specialized palliative home care (SAPV), and the therapeutic and conceptual implications is still lacking.

## Methods

Therefore, a retrospective analysis of all SAPV patients was performed in three German institutions (Landshut, Göttingen, Hamburg). Two of the institutions are closely linked to outpatient haematology/oncology institutions; the third SAPV team is part of a university department which is integral part of a comprehensive cancer center and comprises inpatient and outpatient structures.

All patients being cared for from January 2011 until October 2014 were surveyed. Patients suffering from haematological disease (ICD 10: C81-C95) were subjected to further analysis. If patients suffered from (chronic) haematological disease but

another diagnosis had led to referral to palliative care services, these patients were excluded from detailed analysis.

Demographic and clinical data were documented, comparable to the baseline assessment tool in the Hospice and Palliative Care Evaluation (HOPE [12]; Table 1).

Chart data were provided by the participating institutions in an anonymized version. If data were unavailable, patients were excluded from the respective sub-analysis. Data were analysed descriptively by using Microsoft Excel 2010. The survey was approved by all three local ethics authorities (ethics commissions of Bavaria, Hamburg, and of the University of Göttingen).

## Results

In total, 3,955 patients were surveyed. Of those, 90 were diagnosed having a haematological malignancy, and in 73 patients (in 1.8%), this was the relevant underlying disease that led to SAPV enrollment. Acute leukaemia, multiple myeloma

**Table 1** Chart assessment tool

Demographic data	<ul style="list-style-type: none"> <li>• Registration/chart number</li> <li>• Age</li> <li>• Sex</li> </ul>
Clinical data (haematological malignancy)	<ul style="list-style-type: none"> <li>• Main diagnosis</li> <li>• Date of first diagnosis</li> <li>• Stage/manifestations when SAPV started</li> <li>• Overall condition when SAPV started (ECOG PS; Karnofsky PS)</li> <li>• Summary of haematological treatment</li> <li>• Comorbidities</li> </ul>
Clinical data (SAPV)	<ul style="list-style-type: none"> <li>• Onset and end of SAPV care/length of SAPV care</li> <li>• Speciality of referring institution</li> <li>• Reasons for SAPV referral/symptoms</li> <li>• Intensity and mode of SAPV care (advisory, coordinative, additive, substitutive)</li> <li>• New symptoms and problems occurring during SAPV period</li> <li>• Hospital admissions occurring during SAPV period (frequency, cumulative length of stay, reasons for admission)</li> <li>• Date of death</li> <li>• Place of death</li> </ul>
Interventions during SAPV	Drugs, invasive procedures, diagnostics, blood products, anticancer therapy, nutrition, nursing interventions, physiotherapy, psychosocial interventions, spiritual care, ...
Patient contacts	<ul style="list-style-type: none"> <li>• At home visits</li> <li>• Telephone calls</li> <li>• Ambulance appointments</li> </ul>
Advance Care Planning	<ul style="list-style-type: none"> <li>• Patient's wishes and therapeutic aims</li> <li>• Advance directive</li> <li>• Power of attorney</li> <li>• Health care proxy</li> <li>• Emergency instructions [22]</li> </ul>

and lymphoma were the most common diseases, and chemotherapy is the most common therapy. Fifty-two patients suffered from two or more comorbidities (Table 2).

The vast majority of those patients ( $n = 64$ ; 87.6%) was older than 65 years. Forty-one patients (56.2%) were male, and 32 patients (44.4%) were female.

More than half of patients were referred to SAPV later than 1 year after first diagnosis (24 of 42 patients (57.1%); in 31 patients, no data were available). The overall expectations on SAPV teams when referring patients were documented in 59 patients (in 14 patients, no data were available for this item):

- To have better options to intervene in crises and emergencies ( $n = 29$ )
- To be available 24 h 7 days a week ( $n = 24$ )
- To provide psychological support of patients and relatives ( $n = 17$ )
- To provide sufficient pain therapy ( $n = 14$ )

The reasons for enrollment are summarized in Table 3. Here, focal as well as general problems were found to be quite prevalent.

Palliative home care lasted for 41 days (mean). For the above described 73 patients, 1762 contacts have been documented (1390 home visits, 332 telephone calls and 40 outpatient clinic visits; 24 contacts per patient mean). In most of the contacts, patients were seen by nurses, rather than physicians (1417 contacts; 80.4%).

Seventy percent of the patients (42 of 60 patients; in 13 patients no data were available) died within a 3-month period

**Table 2** Diagnoses, preceding treatment and comorbidities

	% (n)
Underlying haematological diagnoses	
Acute leukaemia	32.9% (n = 24)
Multiple myeloma	24.7% (n = 18)
Lymphoma	24.7% (n = 18)
Chronic lymphocytic leukaemia	13.7% (n = 10)
Other entities	4.1% (n = 3)
Preceding haematological treatment (partly combined; multiple answers possible; data available from 37 patients)	
Chemotherapy	56.8% (n = 21)
Antibody	29.7% (n = 11)
Stem cell transplantation	27.0% (n = 10)
Radiation therapy	18.9% (n = 7)
Most frequent comorbidities data available from 67 patients	
Cardiovascular	70.1% (n = 47)
Psychical/psychiatric	38.8% (n = 26)
Endocrine/metabolic	38.8% (n = 26)
≥2 comorbidities	77.6% (n = 52)

after commencing SAPV. Sixteen of those 60 patients (26.7%) deceased already within 14 days. In 29 patients, their wish to die at home was documented (although the aspired place of death was not assessed routinely). In fact, the majority ( $n = 48$  of those 58 patients where the place of death was documented, 82.8%) eventually died outside hospital (at home ( $n = 38$ ), in a nursing home ( $n = 6$ ) or in hospice ( $n = 4$ )). Only ten patients died in hospital.

During the SAPV period, numerous new clinical problems occurred and were documented in a relevant number of patients ( $n = 27$ ; 37.0%), predominantly pain, psychological symptoms or a deterioration of the overall condition (Table 4).

Therapeutic interventions, that were no genuine assignments of palliative home care (like transfusions or antibiotic therapy), were not documented in detail. But the teams reported that these causative therapies were still prevalent during SAPV care. In particular, blood products were transfused in outpatient clinics (never at home), and intravenous antibiotic therapies were applied if necessary (even at the patient's home). The application of life-prolonging chemotherapies was no exclusion criteria for SAPV.

During the SAPV period, 24 patients were admitted to hospital ( $n = 24$ ) at least once. In total, there were 30 hospital admissions during SAPV. In 23 of all hospital admissions (76.7%), the hospital stay was shorter than 10 days. Leading reasons for this were an overall impaired general status ( $n = 13$ ) or pain ( $n = 7$ ) (Table 5).

Aspects of Advance Care Planning (Table 6) were documented in 52% ( $n = 38$ , in 35 patients, no data were available), mainly a given advance directive ( $n = 23$ ) and a power of attorney ( $n = 23$ ). In most cases, these aspects were discussed even before SAPV started.

**Table 3** Reasons for SAPV enrollment (multiple answers possible)

	Total n = 73
Impaired general status	72
Pain	61
Psychological symptoms	58
Abdominal symptoms	56
Respiratory symptoms	51
Care problems at home	35
Electrolyte and fluid imbalances	29
Neurologic symptoms	19
Bleeding/risk of bleeding	11
Cardiovascular symptoms	8
Ascites/pleural effusions	7
Infection/sepsis/fever	7
Wounds/wound care/pressure sores	7
Impaired blood count/anaemia	6
Others	4

**Table 4** Symptoms and problems occurred within the SAPV period

	Total <i>n</i> = 27
Pain	16
Psychological symptoms (mood, consciousness, coping, ...)	14
Impaired general status	11
Infections (pneumonia, UTI, Herpetic infections, thrush, ...)	9
Dyspnoea	5
Nausea, vomiting	4
Oedema	4
Pressure sores, wound problems	4
Bleeding (e.g. oral mucosa)	4
Drug application problems (by mouth, via port-a-cath, ...)	3
Constipation/diarrhoea	2
Cachexia/weight loss	2
Neurologic symptoms (difficulty swallowing, coordination, ...)	2
Hypotension/hypertension	1
Incontinence	1
Dehydration	1
Stable/no documented new problems during SAPV	46

## Discussion

This multicenter survey demonstrated that specialized home care is feasible and justifiable for patients with haematological malignancies—a group of patients particularly underrepresented in palliative care, especially in palliative home care. To our knowledge, these are the first data for the German

**Table 5** Reasons for hospital admissions during the SAPV period

	Total <i>n</i> = 24
Impaired general status, weakness	13
Pain	7
Psychological symptoms (consciousness, confusion, ...)	5
Infections (pneumonia, UTI, herpetic infections, thrush, ...)	4
Dyspnoea	3
Restlessness	3
Nausea, vomiting	3
Incontinence/UTI	3
Bleeding	2
Drug application problems (by mouth, via port-a-cath, ...)	2
Cardiovascular symptoms	1
Constipation	1
Oedema	1
Pruritus/itching	1
Ulcerations, pressure sores, wound problems	1
Unknown	2

**Table 6** Aspects of Advance Care Planning

	None	Installed before SAPV	Installed during SAPV	No data available
Advance directive	15	20	3	35
Power of attorney	14	20	4	35
Emergency card	36	0	0	37

health care system, and our findings are in line with three other feasibility studies from Italy and Japan, with similar positive outcomes [4, 7, 21].

In our study cohort, derived from three SAPV teams, only 73 out of 3955 patients (1.8%) suffered primarily from a haematological malignancy. However, haematological malignancies contribute to 8.2% of all death cases due to cancer in Germany (18,165 of 220,923 deaths in 2012 [13]), so that the relative number of patients where SAPV could have been applicable is estimated to be accordingly higher. A particularly close doctor-patient relationship in haematological disease has been postulated as an underlying reason for this [8]—this effect might have been even more prominent in our study cohort as two of three recruiting centers provided haematology and palliative care together, and the need for referral to specialized palliative care was perhaps more rarely addressed.

Age distribution and comorbidities in this study cohort were comparable to the general population [13, 23] and their age; symptoms and needs were comparable to other study cohorts investigating SAPV patients suffering from solid cancer [14]. Those were mainly physical symptoms (pain, neurologic/psychiatric, gastrointestinal or respiratory/cardiac), psychosocial or organizational problems [14, 15].

Most of the patients in our study were elderly (>65 years, 87.6%), and most of the patients suffered from acute leukaemia (32.9%). This patient group is at particular risk for severe complications like infections or bleeding and to hospital admissions [24]. SAPV may be particularly helpful to realize home care in this subgroup.

Even if the study design does not allow conclusions on its efficacy, only few SAPV patients had to be admitted to hospital, so that an aspired effect on the hospital readmission rate might be suggested. In only one third of patients, a hospital admission was required, which lasted less than 10 days in 74% of all admitted patients. The hospital admission rate was moderately higher compared to other SAPV patients referred to hospital (<20%) [14, 15], but the motive for referral, a complex symptom burden, was comparable in both groups. For haematological and non-haematological SAPV patients, similar complications and crises were documented during SAPV [15].

Also during home care periods, the documented therapeutic focus was on 24-h availability, treating symptoms and crisis interventions. Coordinative problems, measures of Advance Care Planning or the need for advice in difficult

(ethical) situations were rarely addressed as reasons for SAPV in our cohort of patients suffering from haematological malignancies. This finding may lead to the conclusion that there is even more potential for a more intense use of SAPV in this setting, as SAPV offers numerous more therapeutic options and conceptual support than just treating (physical) symptoms. Especially Advance Care Planning—which was rarely installed during SAPV in our study—may be an important intervention, as patients with a haematological malignancy are particularly prone to acute problems like infections or bleeding. On the other hand, it is possible that especially those patients were envisaged to SAPV where (physical) symptoms were obvious. If so, then our cohort would be afflicted by a selection bias where physical symptoms were prioritized compared to other needs and problems that might otherwise lead to SAPV involvement.

Previous surveys on non-selected SAPV patients revealed a shorter and less intense period of care compared to our haematology group (32 days with 9–10 home visits per patient [14], compared to 41 days with 19 home visits for each haematology patient). Of those home visits, 80% were sufficiently performed by nurses—a detail that suggests future conceptual options for a more comprehensive, but low-threshold home care for haematology patients.

The majority of our patients deceased within 3 months (70.0%) after SAPV enrollment; 26.7% even within the first 2 weeks. An earlier involvement of palliative care services (>3 months before death) was found to be significantly associated with less aggressive care at the end of life (emergency room visits, hospital admissions and in-hospital death) [25]. Correspondingly, another study from MD Anderson Cancer Center found that an underlying haematological malignancy resulted in more aggressive care, compared to a cohort of patients with solid tumours [26]. This US study group described even a general attitude among haematologists towards more aggressive therapies at the end of life compared to physicians treating predominantly patients with solid cancer entities [16, 27]. These intensive therapies and the remaining hope for cure may be perceived as an obstacle for SAPV [27]. For the investigated teams, life-prolonging therapies were no exclusion criteria for enrolment in SAPV [28]. So, a cooperation of haematology and ambulant palliative care is feasible and conclusive.

We found surprisingly few SAPV patients that died in hospital, suggesting a positive effect of SAPV on enabling patients and their families to care for patients at home until the end (which is known to be the most often wished place of death) [14, 15, 29]—as it was demonstrated in our study as well. This might be explained by an earlier clarification of patient preferences towards end of life decisions [30]. Due to the specific course of haematological malignancies and their more unpredictable prognosis and complications, patients with haematological malignancies are more prone to die in the acute hospital setting as compared to patients with solid

tumours [29, 31]. Therefore, SAPV could well contribute to compensate for this effect.

## Limitations

This survey study is limited by its retrospective, chart analysis design. Documentation showed site-divergent deficits that were only in part able to achieve the desired data. This affects the documented psychological burden (which was not assessed by the teams in a structured way, using standardized tools), or the documented number of telephone calls 338 (which is unrealistic), or the documentation of timing of SAPV enrollment within the disease trajectory (which remains incomplete). Further, our study does not allow a direct comparison to non-SAPV patients or to non-haematological patients.

## Conclusions

Our data, according to international surveys, support the conclusion that specialized palliative home care is beneficial for patients with haematological malignancies also in the German health system. These patients exhibit specific clinical and conceptual features different from other non-selected SAPV patients, but differences were less prominent than expected, suggesting that predominantly patients suffering from focal symptoms, especially pain, were enrolled, whereas other needs were less often considered for SAPV. This might disclose a perspective of a broader understanding and a more diverse application of SAPV, earlier in the course of the disease.

**Compliance with ethical standards** The survey was approved by all three local ethics authorities (ethics commissions of Bavaria, Hamburg and of the University of Göttingen).

**Conflict of interest** The authors declare that they have no conflict of interest.

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