Need for additional professional psychosocial and spiritual support in patients with advanced diseases in the course of specialist palliative care – a longitudinal observational study

Anneke Ullrich
Palliative Care Unit, Department of Oncology, Hematology and BMT, University Medical Center Eppendorf, Hamburg

Holger Schulz
Department of Medical Psychology, University Medical Center Eppendorf, Hamburg

Sven Goldbach
Specialist outpatient palliative care team "PalliativPartner Hamburg GbR", Hamburg

Wiebke Hollburg
Specialist outpatient palliative care team "PalliativPartner Hamburg GbR", Hamburg

Annette Rommel
Specialist outpatient palliative care team "Das Palliativteam", Hamburg

Marten Müller
Palliative care ward, Asklepios Hospital Rissen, Hamburg

Denise Kirsch
Specialist outpatient palliative care team "PCT Hamburg-West", Hamburg

Katrin Kopplin-Förtsch
Palliative care ward, Agaplesion Diakonie-Hospital, Hamburg

Julia Messerer
Palliative Care Unit, Department of Oncology, Hematology and BMT, University Medical Center Eppendorf, Hamburg

Louise König
Palliative Care Unit, Department of Oncology, Hematology and BMT, University Medical Center Eppendorf, Hamburg

Frank Schulz-Kindermann
Department of Medical Psychology, University Medical Center Eppendorf, Hamburg

Carsten Bokemeyer
Palliative Care Unit, Department of Oncology, Hematology and BMT, University Medical Center Eppendorf, Hamburg

Karin Oechsle (✉ kaoechsl@uke.de)
Palliative Care Unit, Department of Oncology, Hematology and BMT, University Medical Center Eppendorf, Hamburg

Research Article

Keywords: Palliative care, support needs, specialist palliative care, psychosocial needs, spiritual needs

Posted Date: May 17th, 2021

DOI: https://doi.org/10.21203/rs.3.rs-498989/v1

License: This work is licensed under a Creative Commons Attribution 4.0 International License. Read Full License

Version of Record: A version of this preprint was published at BMC Palliative Care on November 25th, 2021. See the published version at https://doi.org/10.1186/s12904-021-00880-6.
Abstract

Background: We investigated the need for additional professional support and influencing factors in patients (pts) at initiation and in the course of in- and outpatient specialist palliative care (I-SPC/O-SPC).

Methods: Pts entering an urban SPC network consecutively completed questionnaires on psychosocial/spiritual problems and support needs within 72 hours (T0) and within the first 6 weeks (T1) of SPC. Hierarchical linear regression analysis investigated the impact of sociodemographic / clinical variables, psychological / physical burden, social support, and SPC setting on support need.

Results: 425 pts (70 years, 48% female, 91% cancer, 67% O-SPC) answered T0, and 167 T1. At T0, main problems were related to transportation, usual activities, and dependency (83-89%). At T1, most prevalent problems were again related to transportation, usual activities, and additionally light housework (82-86%). At T0, support need was highest for transportation, light housework, and usual activities (35-41%). Cross-sectional comparisons of SPC settings revealed higher problem scores in O-SPC at T0 (p<.039), but not at T1. Support need was higher in O-SPC at T0 (p<.001), but lower at T1 (p=.039). Longitudinal analyses showed a decrease of support need scores over time, independent from the SPC setting. At T0, higher distress (p=.047), anxiety/depression (p<.001), physical burden (p<.001) and I-SPC (p<.001), were associated with higher support need scores (at T1 only higher distress; p=.037).

Conclusion: Need for additional professional psychosocial/spiritual support was identified in up to 40% of pts with higher need at the beginning of OSPC than of ISPC. During SPC, this need decreased in both settings, but got lower in OSPC than in ISPC over time. Psychosocial/spiritual support need was associated with not only with psychological, but also physical burden.

Background:

Palliative care aims to address complex patient problems and needs including physical, psycho-spiritual, and socio-cultural aspects [1]. For cancer patients, still representing the major patient group receiving palliative care in Western countries, professional support in coping with tasks, disease acceptance, generating strength, feeling trust, increasing a sense of control and other psychosocial and spiritual needs is considered as part of standard patient care [2, 3]. However, international experts complain that “the multiple and varying needs of patients are still not being met adequately as part of routine cancer care” [4]. Various studies strengthen this complaint, demonstrating high proportions of unmet needs (50–90%) in patients with cancers across all stages and during the whole disease trajectory [5–8]. It has also been shown that non-cancer patients present with similar main needs compared to a matched cohort of cancer patients, although there were some differences in quality, but not quantity of physical symptom burden [9].

Clinical studies showed that timely inclusion of specialist palliative care (SPC) can not only improve quality of life or symptom burden, but is also associated with a better addressing of patients’ needs especially concerning information and care planning [10]. Psychosocial and spiritual interventions can success fully meet the complex psychosocial and spiritual needs of patients with advanced diseases [11–14].

SPC is offered in inpatient (I-SPC) and outpatient settings (O-SPC). Usually, the SPC setting is chosen according to patients’ individual wishes and needs. However, there are various factors reducing the probability that an outpatient care setting can address the patients’ needs adequately, e.g. patients living alone at home without any family caregivers [15], patients’ age or multi-morbidity [16]. In Germany, O-SPC was established as a billable service in 2005, and O-SPC has become prescribable by law in 2007 [17]. In contrast to the multi-professional principles of SPC in general and to I-SPC, O-SPC only comprises bi-professional care by specialized physicians and nurses, because the services of other professions such as psychologists or therapists are not covered by health insurance [7, 18]. This contrast becomes particularly manifest when patients are discharged to the home care when the psychological and psycho-oncological care is interrupted [7, 19]. In daily practice, voluntary hospice workers often provide home-based psychosocial and spiritual care, while inclusion of professional support is rare and heterogeneous. This might indicate a possible care deficit, especially because up to 50% of terminally ill patients in home settings suffer from mental disorders [20].

The urban area of Hamburg was the first region in Germany that had established a complete and comprehensive network of I- and O-SPC. Therefore, Hamburg can be regarded as a prime example for SPC networks. In this setting it is promising to evaluate if such a comprehensive SPC network can adequately address the complex problems and needs of patients with advanced diseases and terminal illnesses.

The main aim of the present study was to explore psychological, social and spiritual problems of patients at initiation and during SPC and to identify their need for additional professional support in these domains. Secondary aims concerned possible differences between...
patients entering I-SPC versus O-SPC. Further, we investigated the impact of sociodemographic and disease-related variables, physical symptom burden, distress, anxiety/depression and SPC setting on the extent of patients’ need for additional professional support.

**Methods:**

This prospective, observational longitudinal multicenter study was carried out in Hamburg, Germany. In a 12 months’ period between June 2017 and July 2018, patients were consecutively enrolled in six SPC services of an urban network, including three SPC home care services (O-SPC) and three SPC wards (I-SPC). Within 72 hours after first admission, patients were recruited by trained staff of the services. Inclusion criteria were being older than 18 years, suffering from an advanced, life-limiting illness (cancer and non-cancer), and entering in- or outpatient SPC for the first time. Exclusion criteria were cognitive or language problems hampering informed consent and/or answering questionnaires, acute physical or psychological crisis entailing the risk that study participation would significantly increase patients’ burden, and patients’ imminent death. Reasons for study exclusion or non-participation were systematically documented.

Self-report questionnaires were used for data collection, which were handed out personally by staff of the SPC services. Patients’ assistance for answering questionnaires was allowed upon request. Baseline data (T0) were collected within 72 hours after admission to gain information about the patients’ situation at initiation of SPC. Follow-up measurements were scheduled as follows: As long as patients stayed in the same SPC service, questionnaires were administered every four weeks during ongoing SPC. Additionally, patients received a questionnaire before being transitioned to other SPC services or to non-SPC settings. The first questionnaire returned during the first 6 weeks of SPC served as follow-up (T1). Beyond this timeframe, further follow-ups were assessed according to the study protocol, but were not included in the current analysis due to limited sample sizes.

The ethical committee of the General Medical Council of Hamburg has approved the study protocol (PV5062). Written informed consent was obtained before study participation.

**Measurements:**

**Outcome measure**

Problems and needs for additional professional support were measured by an adapted version of the Problems and Needs in Palliative Care Questionnaire – Short Version (PNPCQ-sv) [21, 22]. With permission of its authors, the questionnaire was professionally translated to German language, and comprehensibility was tested in a small convenience sample. In order to focus on psychosocial and spiritual issues, the adapted version omitted physical symptoms. The included 22 items comprised aspects of daily activities, autonomy, need of information, and social, psychological, spiritual and financial issues, which were considered as psychosocial and spiritual issues in the broadest sense.

Two independent sum scores were calculated: the “Extent of psychosocial and spiritual problems” score (short: problem score) and the “Extent of need for additional professional support” (short: support needs score). Each score ranges from 0 to 22 with higher values reflecting a higher number of problems or support needs. Scores for respondents with \( \leq 4 \) missing items were calculated by imputing the mean score for the missing items based on items completed by that individual. In case of \( > 4 \) items (20%), a score was not calculated for that individual. Respondents for which the problem score was not calculated were 9 (2.1%) at T0, and 3 (1.8%) at T1. Likewise, the support needs score was not calculated for 80 respondents (18.8%) at T0 and 27 (16.2%) at T1.

**Potential predictor variables**

The distress thermometer (DT) was used to assess psychological distress within the last week on an 11-point analogue scale. Clinically relevant distress with need of professional psychological support is indicated by a cut-off value of \( \geq 5 \) [23, 24]. The DT includes a problem list with 21 physical symptoms that can be classified to contribute to psychological distress or not. We used the sum score of distressing physical symptoms (“physical symptom count”, 0–21) to estimate the range of patients’ physical symptoms (see supplemental material 1).

The PHQ-4 including a two-item depression scale (PHQ-2), and a two-item anxiety scale (GAD-2) was used for measurement of depressive and anxiety symptoms [25].
In addition, patients reported on sociodemographic characteristics (i.e. age, marital status, educational level, living environment), as well as disease-related data (i.e. primary disease, previous nursing situation).

**Statistical analyses:**

We performed descriptive analyses to examine study population characteristics and to describe patients’ psychosocial and spiritual problems and their need for additional professional support.

Data of patients admitted to I-SCP vs. O-SCP at initiation of SPC (T0) and at follow-up during SPC (T1) were compared cross-sectional using chi-square-tests (Fisher’s exact test if expected values in any cell were below 5) and two-sample t-tests (two-tailed).

The problem scores and support need score at T0 were compared with the respective scores at T1 using repeated measures ANOVA (RM-ANOVA) with setting (O-SCP vs. I-SCP) as a main factor. As measures of effect, we calculated partial eta-squared (\(\eta_p^2\); small = 0.01, medium = 0.06, large = 0.14).

Two hierarchical linear regression models (enter method) were used to investigate the impact of sociodemographic and disease-related variables, psychological and physical burden, and SPC setting on the extent of patients’ need for additional support. Support needs scores at T0 and at T1 were defined as dependent variables, respectively. Sociodemographic variables were added in step 1 (Model 1), disease-related variables at step 2 (Model 2), proxy-variables for social support at step 3 (Model 3), physical burden at step 4 (Model 4), and variables reflecting psychological burden at step 5 (Model 5). Categorical predictor variables were dichotomized. Examination of correlations among the predictor variables revealed no problems with multicollinearity. Missing data were handled using the list wise deletion method.

All significance tests were two-tailed using a significance level of \(\alpha < .05\). Analyses were completed using SPSS software version 25.0 (IBM, 2017).

**Results:**

**Patient recruitment and characteristics:**

During recruitment, 1,713 patients were admitted to the 6 participating services. Of these, 713 (42%) were eligible for study inclusion, and 443 were willing to participate (61%). Among 425 who returned the baseline questionnaires (T0), 285 were admitted to O-SCP (67%) and 140 to I-SCP (33%). At follow-up during SPC (T1), 167 patients (39%) answered a questionnaire. At this time point, 130 (78%) were treated in O-SCP and 37 (22%) in I-SCP (Fig. 1).

Overall, at initiation of SPC (T0) 52% of 425 patients were male (mean age 69.7 ± 12.5 years) and 91% suffered from cancer. Patients admitted to O-SCP were significantly younger (\(p < .001\)) and had needed less intensive nursing prior to SPC (\(p = .008\)) than in I-SCP (Table 1).
### Table 1
Patient characteristics at baseline (N = 425).

|                        | Whole sample (N = 425) | O-SPC (N = 285) | I-SPC (N = 140) | p       |
|------------------------|------------------------|-----------------|-----------------|---------|
| Age, M (SD)            | 69.7 (12.5)            | 71.4 (11.3)     | 66.2 (14.0)     | < .001  |
| Age groups             |                        |                 |                 |         |
| ≤ 50                   | 28 (6.6)               | 15 (5.3)        | 13 (9.3)        | .013 b  |
| 51–60                  | 65 (15.3)              | 35 (12.3)       | 30 (21.4)       |         |
| 61–70                  | 110 (25.9)             | 71 (24.9)       | 39 (27.9)       |         |
| 71–80                  | 136 (32.0)             | 99 (34.7)       | 37 (26.4)       |         |
| ≥ 81                   | 86 (20.2)              | 65 (22.8)       | 21 (15.0)       |         |
| Gender                 |                        |                 |                 |         |
| Male                   | 220 (51.9)             | 146 (51.4)      | 74 (52.9)       | .779 b  |
| Female                 | 205 (48.1)             | 138 (48.6)      | 66 (47.1)       |         |
| Primary disease        |                        |                 |                 |         |
| Gastrointestinal cancer| 104 (24.5)             | 63 (22.1)       | 41 (29.3)       | .209 b  |
| Cancer of the respiratory system | 78 (18.4) | 60 (21.1) | 18 (12.9)   |         |
| Urogenital and breast cancer | 136 (32.0) | 90 (31.6) | 46 (32.9)   |         |
| Other malignancies     | 72 (16.9)              | 47 (16.5)       | 25 (17.9)       |         |
| Non-malignant diseases | 35 (8.2)               | 25 (8.8)        | 10 (7.1)        |         |
| Nationality            |                        |                 |                 |         |
| German                 | 395 (95.9)             | 260 (94.5)      | 135 (98.5)      | .055 b  |
| Religious confession   |                        |                 |                 |         |
| Yes                    | 235 (57.5)             | 150 (54.9)      | 85 (62.5)       | .14 b 5 |
| Family status          |                        |                 |                 |         |
| Single                 | 80 (18.9)              | 46 (16.2)       | 34 (24.3)       | .105 b  |
| Married, life partnership | 211 (49.8)            | 143 (50.4)      | 68 (48.6)       |         |
| Divorced, widowed      | 133 (31.4)             | 95 (33.5)       | 38 (27.1)       |         |
| Children               |                        |                 |                 |         |
| Yes                    | 302 (71.4)             | 205 (72.2)      | 97 (69.8)       | .608 b  |
| Living environment     |                        |                 |                 |         |
| Living alone           | 135 (32.3)             | 90 (32.4)       | 45 (32.1)       | .427 b  |
| Living alone, but family nearby | 48 (11.5) | 28 (10.1) | 20 (14.3)   |         |
| Living with family     | 235 (56.2)             | 160 (57.6)      | 75 (53.6)       |         |
| Education              |                        |                 |                 |         |
| High school (12–13 years) | 129 (31.2)            | 81 (29.5)       | 48 (34.5)       | .566 b  |
| Junior high school (10 years) | 117 (28.3)            | 79 (28.7)       | 38 (27.3)       |         |
| Elementary school (≤ 9 years) | 168 (40.6)            | 115 (41.8)      | 53 (38.1)       |         |
| Previous nursing situation |                    |                 |                 |         |
| No nursing             | 78 (19.3)              | 41 (15.2)       | 37 (27.4)       | .008 b  |
| By relatives only      | 151 (37.3)             | 99 (36.7)       | 52 (38.5)       |         |
| Nursing service only   | 116 (28.6)             | 88 (32.6)       | 28 (20.7)       |         |

Abbreviations: O-SPC, outpatient specialist palliative care; I-SPC, inpatient specialist palliative care; pts, patients

* a T-test (two-tailed), b Chi²-Test

Significant group differences are marked in bold.
Cross-sectional analyses of problems at initiation and during SPC:

At initiation of SPC (T0), the five most prevalent problems were “transportation” (88.9%), “difficulties in continuing the usual activities” (88.9%), “being dependent of others” (82.6%), “doing light housework” (82.1%), and “body care, washing, dressing or toilet” (70.4%). Problems in the psychological and spiritual domains were reported less often, but were still indicated by 44 to 69% (psychological issues) and 45 to 55% (spiritual issues) of patients. A significant difference between the O-SPC and I-SPC group was observed in 6 of 22 given problems. Except for one aspect, these problems were more frequent in O-SPC, resulting in a higher mean problem score in the O-SPC vs. I-SCP group (11.7 vs. 11.1, p = .039).

During SPC (T1), the five most common problems were “transportation” (85.5%), “difficulties in continuing the usual activities” (85.3%), “doing light housework” (81.7%), “difficulty coping with the unpredictability of the future” (67.3%), and “body care, washing, dressing or toilet” (67.1%). Again, psychological (39 to 67%) and spiritual problems (37 to 58%) were indicated less often. Problem scores did not differ significantly between patients receiving O-SPC vs. I-SPC at this point of time (p = .278.). However, patients receiving I-SPC more often reported problems regarding “transportation” (p = .049) and “finding others not receptive to talking about the disease” (p = .003, Table 2).
Table 2
Cross-sectional comparisons of patients’ psychosocial and spiritual problems during O-SPC vs. I-SPC

|                                | At initiation of SPC (T0) | During SPC (T1) |
|--------------------------------|---------------------------|-----------------|
|                                | (N = 425)                 | (N = 167)       |
| Whole sample                   |                           |                 |
| (N = 425)                      | (N = 285)                 | (N = 140)       |
| O-SPC                          |                           |                 |
| (N = 285)                      |                           |                 |
| I-SPC                          |                           |                 |
| (N = 140)                      |                           |                 |
| Psychosocial and spiritual problems (PNPCQ-sv) | n (%) | n (%) | p | n (%) | n (%) | n (%) | p |
| Daily activities               |                           |                 |
| Body care, washing, dressing, or toilet | 299 (70.4) | 204 (72.9) | .286 | 112 (67.1) | 84 (67.2) | 28 (66.7) | .949 |
| Transportation                 | 378 (88.9)                | 261 (92.9)      | .005 | 141 (85.5) | 109 (76.2) | 32 (88.6) | .049 |
| Doing light housework          | 349 (82.1)                | 244 (87.1)      | .004 | 134 (81.7) | 102 (82.9) | 32 (78.0) | .484 |
| Autonomy                       |                           |                 |
| Difficulties in continuing the usual activities | 378 (88.9) | 256 (91.1) | .382 | 139 (85.3) | 105 (85.4) | 34 (85.0) | .955 |
| Difficulty to give tasks out of hands | 232 (54.6) | 154 (55.0) | .650 | 88 (53.3) | 62 (50.0) | 26 (63.4) | .136 |
| Being dependent of others      | 351 (82.6)                | 235 (82.5)      | .798 | 130 (30.6) | 97 (77.6) | 33 (80.5) | .679 |
| Experiencing loss of control over one’s life | 272 (64.0) | 180 (64.1) | .412 | 93 (56.0) | 65 (52.4) | 28 (66.7) | .108 |
| Social issues                  |                           |                 |
| Problems in the relationship with life companion | 85 (20.0) | 65 (23.2) | .040 | 24 (14.6) | 15 (12.1) | 9 (21.4) | .137 |
| Difficulties in talking about the disease with life companion | 128 (30.1) | 94 (33.5) | .066 | 34 (20.5) | 24 (19.2) | 10 (24.4) | .475 |
| Finding it difficult to talk about the disease, because of not wanting to burden others | 225 (52.9) | 156 (55.9) | .320 | 67 (40.1) | 49 (39.2) | 18 (42.9) | .676 |
| Finding others not receptive to talking about the disease | 153 (36.0) | 105 (37.2) | .661 | 46 (28.0) | 27 (22.0) | 19 (46.3) | .003 |
| Difficulties in finding someone to talk to | 145 (34.1) | 100 (35.5) | .564 | 45 (27.4) | 33 (26.8) | 12 (29.3) | .762 |
| Psychological issues           |                           |                 |
| Depressed mood                 | 188 (44.3)                | 131 (46.5)      | .319 | 64 (38.6) | 48 (38.7) | 16 (38.1) | .944 |
| Difficulty coping with the unpredictability of the future | 291 (68.5) | 200 (71.4) | .296 | 111 (67.3) | 84 (67.7) | 27 (65.9) | .823 |
| Difficulties to show emotions  | 212 (49.9)                | 143 (50.7)      | .891 | 71 (43.6) | 49 (39.8) | 22 (55.0) | .093 |

Abbreviations: SPC, specialist palliative care; pts, patients; O-SOC, outpatient specialist palliative care; I-SPC, inpatient specialist palliative care; PNPCQ-sv, Problems and Needs in Palliative Care Questionnaire – Short Version

a Chi²-Test, b T-test (two-tailed)

Significant group differences are marked in bold.
| Spiritual issues                                      | At initiation of SPC (T0) (N = 425) | During SPC (T1) (N = 167) |
|------------------------------------------------------|-------------------------------------|---------------------------|
| Difficulties to be engaged usefully                   | 206 (48.5)                          | 86 (52.4)                 |
|                                                      | 144 (52.0)                          | 66 (53.2)                 |
|                                                      | 62 (44.9)                           | 20 (50.0)                 |
|                                                      |                                     |                           |
| Difficulties to be of avail of others                 | 233 (54.8)                          | 96 (58.5)                 |
|                                                      | 160 (58.0)                          | 68 (55.3)                 |
|                                                      | 73 (53.3)                           | 28 (68.3)                 |
|                                                      |                                     |                           |
| Difficulties concerning the meaning of death          | 192 (45.2)                          | 60 (37.3)                 |
|                                                      | 138 (49.8)                          | 46 (38.0)                 |
|                                                      | 54 (39.7)                           | 14 (35.0)                 |
|                                                      |                                     |                           |
| Difficulties to accept the disease                    | 233 (54.8)                          | 83 (50.9)                 |
|                                                      | 168 (59.2)                          | 61 (49.6)                 |
|                                                      | 65 (47.1)                           | 22 (55.0)                 |
|                                                      |                                     |                           |
| Financial problems                                    |                                     |                           |
| Extra expenditures because of the disease             | 125 (29.4)                          | 40 (27.4)                 |
|                                                      | 85 (30.5)                           | 29 (23.8)                 |
|                                                      | 40 (29.2)                           | 11 (27.5)                 |
|                                                      |                                     |                           |
| Loss of income because of the disease                 | 71 (16.7)                           | 28 (17.5)                 |
|                                                      | 39 (14.1)                           | 20 (16.7)                 |
|                                                      | 32 (23.7)                           | 8 (20.0)                  |
|                                                      |                                     |                           |
| Need of information                                   |                                     |                           |
| Insufficient information, e.g. about the disease and  | 140 (32.9)                          | 38 (23.5)                 |
| its treatment, aids and agencies that can provide    | 105 (37.9)                          | 27 (22.1)                 |
| help, alternative healing methods.                    | 35 (25.4)                           | 11 (27.5)                 |
|                                                      |                                     |                           |
| Score "Extent of psychosocial and spiritual problems"| 11.7 (4.9)                          | 10.5 (4.7)                |
| (0–22)c, M (SD)                                       | 11.7 (4.9)                          | 11.2 (4.9)                |
|                                                      | 11.1 (4.0)                          | .278 b                    |

Abbreviations: SPC, specialist palliative care; pts, patients; O-SOC, outpatient specialist palliative care; I-SPC, inpatient specialist palliative care; PNPCQ-sv, Problems and Needs in Palliative Care Questionnaire – Short Version

| a Chi²-Test, b T-test (two-tailed) |

Significant group differences are marked in bold.

Cross-sectional analyses of need for additional professional support at initiation and during SPC:

At T0, the five most common needs for additional professional support were "transportation" (40.5%), “doing light housework” (38.4%), “difficulties in continuing the usual activities” (35.2%), “difficulty coping with the unpredictability of the future” (29.9%), and “being dependent of others” (28.9%). Need for additional professional support was indicated by 15.3 to 29.9% of patients concerning psychological problems, and 18.4 to 24.7% concerning spiritual problems. A significant difference between the O-SPC and I-SPC group was observed in 9 of 22 given needs, including all spiritual aspects. These needs were consistently more prevalent in O-SPC compared to I-SPC. Also, the mean needs score showed to be significantly higher in patients receiving O-SPC (6.4 vs. 4.1; p < .001).

At T1, need for additional professional support has decreased in most aspects. Among 167 patients, the five most frequent needs for more support related to "transportation" (24.0%), “doing light housework” (19.9%), “being dependent of others” (19.7%), “difficulties in continuing the usual activities” (19.6%), and “difficulty coping with the unpredictability of the future” (13.2%). Need for additional support was reported by 3.2 to 13.2% of patients for psychological problems, and by 9.0 to 11.8% for spiritual problems. During SPC (T1), the mean support need score was significantly lower in O-SPC compared to I-SPC (1.7 vs 3.2; p = .038). At the level of single needs, “difficulties to accept the disease” was experienced differently across SPC settings with patients in O-SPC reporting less need for support (7.0% vs. 18.9%, p = .034; Table 3).
Table 3  
Cross-sectional comparisons of patients’ need for additional professional psychosocial and spiritual support during O-SPC vs. I-SPC

|                      | At initiation of SPC (T0) | During SPC (T1) |
|----------------------|---------------------------|-----------------|
|                      | (N = 425)                 | (N = 167)       |
| Whole sample         | O-SPC (N = 285)           | I-SPC (N = 140) |
|                      | Whole sample (N = 425)    |                 |

**Need for additional psychosocial and spiritual support (PNPCQ-sv)**

|                      | Whole sample yes (%)     | O-SPC yes (%)   | I-SPC yes (%)   |
|----------------------|--------------------------|----------------|----------------|
| Daily activities:    |                          |                |                |
| Body care, washing, dressing, or toilet | 121 (28.5) | 96 (34.7) | 25 (18.0) |
|                      | p < .001                 | a              |                |
| Transportation       |                          |                |                |
|                      | 172 (40.5)               | 121 (45.0)     | 51 (38.6)     |
|                      | p = .228                 | a              |                |
| Doing light housework|                          |                |                |
|                      | 163 (38.4)               | 120 (45.1)     | 43 (32.8)     |
|                      | p = .019                 | a              |                |
| Autonomy:            |                          |                |                |
| Difficulties in continuing the usual activities | 150 (35.2) | 99 (37.8) | 51 (38.1) |
|                      | p = .958                 | a              |                |
| Difficulty to give tasks out of hands | 85 (20.0) | 60 (22.0) | 25 (18.8) |
|                      | p = .460                 | a              |                |
| Being dependent of others | 123 (28.9) | 85 (31.3) | 38 (28.6) |
|                      | p = .582                 | a              |                |
| Experiencing loss of control over one’s life | 114 (26.8) | 78 (28.5) | 36 (26.9) |
|                      | p = .735                 | a              |                |
| Social issues:       |                          |                |                |
| Problems in the relationship with life companion | 38 (8.9) | 29 (10.4) | 9 (6.6) |
|                      | p = .207                 | a              |                |
| Difficulties in talking about the disease with life companion | 59 (13.9) | 46 (19.0) | 13 (10.9) |
|                      | p = .051                 | a              |                |
| Finding it difficult to talk about the disease, because of not wanting to burden others | 96 (22.6) | 72 (30.0) | 24 (19.5) |
|                      | p = .032                 | a              |                |
| Finding others not receptive to talking about the disease | 54 (12.7) | 43 (17.9) | 11 (9.3) |
|                      | p = .033                 | a              |                |
| Difficulties in finding someone to talk to | 78 (18.4) | 54 (22.4) | 24 (20.3) |
|                      | p = .655                 | a              |                |
| Psychological issues:|                          |                |                |
| Depressed mood       | 75 (17.6)                | 57 (23.2)      | 18 (15.1)     |
|                      | p = .075                 | a              |                |

Abbreviations: SPC, specialist palliative care; pts, patients; O-SOC, outpatient specialist palliative care; I-SPC, inpatient specialist palliative care; PNPCQ-sv, Problems and Needs in Palliative Care Questionnaire – Short Version

a Chi2-Test; b Fisher’s Exact Test; c T-test (two-tailed); d Higher scores reflect a greater number of needs for which additional professional psychosocial and spiritual support was indicated

Significant group differences are marked in bold.
### At initiation of SPC (T0) (N = 425)

| Difficulty                                      | At T0 (N = 425) | During SPC (T1) (N = 167) |
|-------------------------------------------------|------------------|---------------------------|
| Difficulty coping with the unpredictability of the future | 127 (29.9)       | 20 (13.2)                 |
| Difficulties to show emotions                     | 65 (15.3)        | 7 (4.5)                   |
| Spiritual issues:                                 |                  |                           |
| Difficulties to be engaged usefully              | 78 (18.4)        | 13 (9.0)                  |
| Difficulties to be of avail of others            | 85 (20.0)        | 17 (11.8)                 |
| Difficulties concerning the meaning of death     | 94 (22.1)        | 16 (10.3)                 |
| Difficulties to accept the disease               | 105 (24.7)       | 15 (9.9)                  |
| Financial problems:                              |                  |                           |
| Extra expenditures because of the disease        | 66 (15.5)        | 9 (5.8)                   |
| Loss of income because of the disease            | 41 (9.6)         | 9 (5.8)                   |
| Need of information:                             |                  |                           |
| Insufficient information, e.g. about the disease and its treatment, aids and agencies that can provide help, alternative healing methods. | 116 (27.3)       | 15 (9.6)                  |
| Score "Extent of need for additional professional support" (0–22) M (SD) | 6.4 (6.5)        | 1.7 (2.9)                 |

Abbreviations: SPC, specialist palliative care; pts, patients; O-SOC, outpatient specialist palliative care; I-SPC, inpatient specialist palliative care; PNPCQ-sv, Problems and Needs in Palliative Care Questionnaire – Short Version

### Longitudinal analyses of problems and need for additional professional support:

Comparing problem scores at T0 with T1, no significant effects were detected by RM-ANOVA. Analyzing the course of the support needs scores, significant improvement could be demonstrated over time (large time effect: p < .001, $\eta^2_p = .106$), meaning that less needs were reported to be unmet. However, we found no significant effects of the setting (O-SPC/I-SPC) or interaction effects of time and setting (Table 4).
Table 4  
Comparison of the total scores of psychosocial and spiritual problems as well as need for additional professional support assessed at initiation of specialist palliative care (T0) and at follow-up (T1) using repeated measures ANOVA

|                      | 0-SPC | l-SPC | Main Effect Time | Main Effect Setting | Setting x Time Interaction |
|----------------------|-------|-------|------------------|---------------------|---------------------------|
|                      | M (SD)| M (SD)| df    | F     | p    | df    | F     | p    | ngp2 | df    | F     | p    | ngp2 |
| Score “Extent of psychosocial and spiritual problems” (0–22) |       |       |       |       |      |       |       |      |      |       |       |      |      |
| At initiation of SPC (T0) | 11.2 (4.9) | 10.8 (3.8) | 1 | .797 | .373 | .005 | 1 | .000 | .996 | .000 | 1 | .700 | .404 | .004 |
| During SPC (T1)            | 10.5 (4.7) | 10.8 (4.7) |       |       |      |       |       |      |      |       |       |      |      |
| Score “Extent of need for additional professional support” (0–22) |       |       |       |       |      |       |       |      |      |       |       |      |      |
| At admission (T0)          | 4.8 (5.8) | 3.6 (3.5) | 1 | 13.158 | <.001 | .106 | 1 | .158 | .692 | .001 | 1 | 2.087 | .151 | .018 |
| During SPC (T1)            | 1.9 (3.3) | 2.4 (3.8) |       |       |      |       |       |      |      |       |       |      |      |

Abbreviations: SPC, specialist palliative care; M, mean; SD, standard deviation; df, degrees of freedom; F, F-statistic; ngp2, partial eta square; p, probability of type I error

Significant p-values are marked in bold.

Potential predictors for additional professional psychosocial or spiritual support needs at initiation and during SPC:

Predictors for the extent of support needs at both time points identified by hierarchical linear regression analyses.

At T0, variables of step 1 to 3 (sociodemographic, disease-related, and proxy-variables for social support) only explained up to 5% of the variance in the support needs score, and SPC setting showed to be the single associate. Physical burden, tested in step 4, explained an additional 25% of variance. Psychological factors, tested in step 5, explained an additional 10% of variance. Higher distress (p = .047) and higher level of anxiety/depressive symptoms (p < .001) were associated with the support needs score. Additionally, SPC setting (p < .001) and physical burden (p < .001) remained significantly associated in this final model.

At T1, variables tested in step 1 to 3 only explained up to 8% of the variance with primary disease being the only significant predictor. Physical burden, tested in step 4, explained an additional 4% of variance. Psychological factors, tested in step 5, explained an additional 7% of variance when controlling the other factors. Higher distress (p = .037) was associated with the support needs score, and neither of the other factors remained significantly associated in the final model (Table 5).
Table 5
Summary of hierarchical regression analysis for variables predicting the extent of need for additional professional psychosocial and spiritual support when first entering SPC (T0) and during SPC (T1)

| Predictor variables | Model 1 | Model 2 | Model 3 | Model 4 | Model 5 |
|---------------------|---------|---------|---------|---------|---------|
|                     | ß       | ß       | ß       | ß       | ß       |

Score “Need for additional professional support at initiation of SPC” (T0, N = 314) b

- Age
  - Model 1: -.01
  - Model 2: -.03
  - Model 3: -.05
  - Model 4: -.02
  - Model 5: -.02

- Gender (0, female; 1, male)
  - Model 2: .01
  - Model 3: .15
  - Model 4: .01
  - Model 5: .02
  - Model 6: -.03

- Primary disease (0, non-cancer; 1, cancer)
  - Model 2: -.12
  - Model 3: -.11
  - Model 4: -.10
  - Model 5: -.04

- SPC setting (0, inpatient; 1, outpatient)
  - Model 3: .17**
  - Model 4: .17**
  - Model 5: .21***
  - Model 6: .17***

- Care site prior SPC (0, at home; 1, nursing home/hospital)
  - Model 1: -.04
  - Model 2: -.04
  - Model 3: -.04
  - Model 4: -.03

- Having children (0, no; 1, yes)
  - Model 1: -.03
  - Model 2: -.03
  - Model 3: -.01
  - Model 4: -.01

- Living situation (0, living alone; 1, with relatives or relatives nearby)
  - Model 1: -.08
  - Model 2: -.12*
  - Model 3: -.09

- Physical symptom count (0–21)
  - Model 3: .51***
  - Model 4: .33***

- Distress (DT; 0–10)
  - Model 5: .10*

- Anxiety/depressive symptoms (PHQ-4; 0–12)
  - Model 5: .33***

R²
- Model 1: .00
- Model 2: .04
- Model 3: .05
- Model 4: .30
- Model 5: .40

Adjusted R²
- Model 1: -.01
- Model 2: .03
- Model 3: .03
- Model 4: .28
- Model 5: .38

F for change in R²
- Model 1: .04
- Model 2: 4.4
- Model 3: 1.4
- Model 4: 109.73
- Model 5: 26.02

Score “Need for additional professional support during SPC” (T1, N = 129) b

- Age
  - Model 1: -.11
  - Model 2: -.13
  - Model 3: -.12
  - Model 4: -.14
  - Model 5: -.10

- Gender (0, female; 1, male)
  - Model 2: .08
  - Model 3: .09
  - Model 4: .08
  - Model 5: .08

- Primary disease (0, non-cancer; 1, cancer)
  - Model 2: -.18*
  - Model 3: -.19*
  - Model 4: -.19*
  - Model 5: -.14

- SPC setting (0, inpatient; 1, outpatient)
  - Model 2: -.16
  - Model 3: -.15
  - Model 4: -.12
  - Model 5: -.10

- Care site prior SPC (0, at home; 1, nursing home/hospital)
  - Model 2: -.08
  - Model 3: -.08
  - Model 4: -.07
  - Model 5: -.04

- Having children (0, no; 1, yes)
  - Model 2: -.03
  - Model 3: -.01
  - Model 4: .03

Abbreviations: ß, Standardized regression coefficients; SPC, specialist palliative care; DT, Distress Thermometer; PHQ-4, Patient Health Questionnaire 4-item version

Hierarchical linear regression analysis (enter method). Step 1: demographic variables (age, sex), step 2: care-related variables (primary disease, SPC setting, care site prior SPC); step 3: proxy-variables for social support (children, living situation), step 4: Physical burden (physical symptom count), step 5: variables reflecting psychological burden (distress, anxiety/depressive symptoms)

a All potential predictor variables were measured at onset of specialist palliative care (T0), b Reduced sample size due to missing values (analyzed by listwise deletion)

* p < .05
** p < .01
*** p < .001
•
## Predictor variables

| Predictor variables | Model 1 | Model 2 | Model 3 | Model 4 | Model 5 |
|---------------------|---------|---------|---------|---------|---------|
|                     | \( \beta \) | \( \beta \) | \( \beta \) | \( \beta \) | \( \beta \) |
| Living situation (0, living alone; 1, with relatives or relatives nearby) | \(-.03\) | \(-.07\) | \(-.08\) |         |         |
| Physical symptom count (0–21) | \(.21^*\) | 1.0 |         |         |         |
| Distress (DT; 0–10) |         | 2.0\(^*\) |         |         |         |
| Anxiety/depressive symptoms (PHQ-4; 0–12) | \(.19\) |         |         |         |         |
| \( R^2 \) | \(.02\) | \(.08\) | \(.08\) | \(.12\) | \(.19\) |
| Adjusted \( R^2 \) | \(.00\) | \(.04\) | \(.03\) | \(.06\) | \(.13\) |
| \( F \) for change in \( R^2 \) | 1.04 | 2.7 | \(.18\) | 5.67 | 5.30 |

Abbreviations: \( \beta \), Standardized regression coefficients; SPC, specialist palliative care; DT, Distress Thermometer; PHQ-4, Patient Health Questionnaire 4-item version

Hierarchical linear regression analysis (enter method). Step 1: demographic variables (age, sex), step 2: care-related variables (primary disease, SPC setting, care site prior SPC); step 3: proxy-variables for social support (children, living situation), step 4: Physical burden (physical symptom count), step 5: variables reflecting psychological burden (distress, anxiety/depressive symptoms)

\(^a\) All potential predictor variables were measured at onset of specialist palliative care (T0), \(^b\) Reduced sample size due to missing values (analyzed by listwise deletion)

\* \( p < .05 \)

\** \( p < .01 \)

\*** \( p < .001 \)

\.

\.

## Discussion

This prospective longitudinal study evaluated psychosocial and spiritual problems of patients receiving I-SPC or O-SPC, their need for additional professional psychosocial and spiritual support and predictors for a higher number of support needs.

### Psychosocial and spiritual problems:

The most prevalent problems of patients at initiation of SPC were problems in the field of daily activities. During SPC, four of the five most frequent problems were still related to daily activities. However, with “difficulty coping with the unpredictability of the future” as fourth frequent problem, a psychological aspect gained on impact. In line, in a previous German study patients receiving O-SPC most commonly reported problems concerning daily activities (fatigue, getting around, eating, bathing/dressing) [26]. The impact of such impairments is also emphasized by a study reporting that problems in the area of functioning were most frequently complained by patients receiving SPC [27]. In our study, spiritual problems were less frequently identified than psychological problems, but still concerned about 40% of patients at both assessments. This matches with previous studies reporting an importance of spirituality / spiritual aspects during palliative care in about 30–40% of patients [9, 28].

Comparing O-SPC and I-SPC, problems tended to be more frequent in the O-SPC group at initiation of SPC, which also reflected in significantly higher problem scores. Despite these differences, patients from both settings showed relevant problems requiring multi-professional care. In contrast, the setting did not influence problem scores at follow-up during SPC; however, prevalence of two single problems (“transportation”, “finding others not receptive to talking about the disease”) was significantly higher in the I-SPC group. In a retrospective study comparing O-SPC and I-SPC, O-SPC patients had worse function and higher need for care planning and family support [29].
Longitudinal analyses of problem scores showed no significant effects of time and setting. This might not be surprising as the patients’ advanced diseases progress over time, and SPC could only maintain stability of symptoms and problem burden.

Need for additional professional psychosocial and spiritual support:

The need for additional support was lower than the extent of the corresponding problems at both assessments indicating that patients might not expect or want professional support for every problem. Some problems might be addressed by informal support, e.g. family caregivers, or patients might prefer to cope with some problems themselves. At initiation of SPC, the three most common needs for additional support concerned daily activities, followed by two psychological issues regarding the difficulty to cope with the unpredictability of the future and being dependent of others. During SPC, the need for additional support has decreased in most aspects with the same needs representing the “top five”. Literature on patients’ support needs mainly relates on cancer patients [8, 27, 30–39]. These studies also demonstrate that daily living, practical support, information and emotional/psychological support consistently represent the most prevalent unmet support needs [8, 27, 30–39]. In line with the results from our study, a repeatedly mentioned psychological problem causing support need is the unpredictability of future [8, 35, 38].

Additional need for professional spiritual support was lower with about 20% at initiation of SPC and about 10% during follow-up indicating that such support is needed by a subgroup of patients. However, studies strengthen the lack of spiritual support even during SPC in a still relevant number of patients [9].

Comparing SPC settings, patients scored significantly higher additional support need when entering O-SPC. Interestingly, during SPC, the need for additional psychosocial and spiritual support was higher in I-SPC. However, higher support needs during inpatient compared to outpatient care in cancer patients have been demonstrated [30].

Longitudinal analyses of patients’ need for additional support showed a significant improvement over time, but without any difference between the two SPC settings. This result demonstrates that the two different SPC setting reach the needs of the referred patient cohorts, which strengthens the results of a previous study that also demonstrated that SPC could reach the needs of their target group [36].

Factors of impact on additional professional support need:

At initiation of SPC, higher support need scores were associated with higher physical symptom burden, higher distress, higher levels anxiety/depression and I-SPC setting. In contrast, during SPC, higher distress revealed to be the only predictor of support needs. Previous studies have also reported significant effects of distress and problem or symptom burden on patients’ support needs [26]. In our study, sociodemographic or disease-related factors were not identified to be predictive, which is in line with previous studies that could not find any or only partial associations between sociodemographic or medical/illness-related factors in patients with advanced diseases [26, 35, 37]. Only one study on older cancer patients had observed that non-white, divorced or never married patients had higher unmet social support needs [31].

Strengths and limitations:

This study has some strengths, e.g. the prospective longitudinal design, consecutive patient recruitment within an established SPC network, and systematic documentation of non-response. In addition, our study specifically evaluates the need for professional support in patients receiving SPC. Previous study mainly analyzed “unmet needs” which does not clarify if the patients expect professional or non-professional support, e.g. from family caregivers.

However, there are some limitations that have to be noticed. Our SPC network is located in an urban region and it remains unclear if these results could be transferred to patients in more rural areas. Further, our cohort includes about 90% cancer patients with a relevant underrepresentation of problems and needs of non-cancer patients. However, it represents a typical cohort during SPC in Europe where up to 90% of SPC patients suffer from oncological diseases [40]. Previous studies also suggest that the problems and needs are similar between cancer and non-cancer patients [9, 41]. However, two studies comparing cancer and non-cancer patients, suggest that non-cancer patients present with lower functional status when first entering SPC [41, 42].

We included aspects of daily living as psychosocial aspects when using the PNPC-sv, while some other questionnaires define them as a separate or physical category. However, the PNPC-sv is one of the two most commonly used questionnaire in needs assessment at least in cancer patients [33]. Overall, the different questionnaires used for needs assessment hamper comparability of data in general [32, 33].

In conclusion, patients entering SPC suffer from a relevant number of problems mainly concerning limited daily activities. Interestingly, psychological and spiritual problems were more frequent in patients entering O-SPC. This difference is balanced during SPC without any
difference in general, but a higher frequency of single problems during SPC. The need for additional professional support is lower than the corresponding extent of problems indicating that patients do not expect or want professional support for all of their problems. Thus, assessments in routine care should be used that allow to distinguish between problems and (unmet) needs, which are two different concepts. Additional professional support is mainly requested concerning aspects of daily living, dependency and coping with the unpredictability of the future. Spiritual problems and need for additional professional support are less frequent than psychological. Patients’ need for additional support decreases during SPC, but did not show any difference between the two SPC settings, despite of the provision of multi-professional care during I-SPC and bi-professional care during O-SPC. Support need is influenced by psychological distress and physical symptom burden, but not sociodemographic or disease-related factors.

Declarations

Ethics approval and consent to participate

Ethical committee approval was granted by the General Medical Council of Hamburg, Germany (PV5062).

All methods were carried out in accordance with relevant guidelines and regulations.

All study participants provided written informed consent for study participation, data analysis and publication.

Consent for publication

Not applicable

Competing interests

Authors declare no competing interest.

Availability of data and material

The datasets used and analysed during the current study are available from the corresponding author on reasonable request.

Funding:

This work was funded by the German Cancer Aid ("Deutsche Krebshilfe e.V.", grant number: 70112144).

The funders had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript.

Author contributions:

Conception and design: Karin Oechsle, Holger Schulz, Frank Schulz-Kindermann

Provision of study materials or patients: Sven Goldbach, Wiebke Hollburg, Annette Rommel, Marten Müller, Denise Kirsch, Kathrin Kopplin-Foertsch, Carsten Bokemeyer

Collection and assembly of data: Sven Goldbach, Wiebke Hollburg, Annette Rommel, Marten Müller, Denise Kirsch, Kathrin Kopplin-Foertsch, Anneke Ullrich, Julia Messerer, Louise König

Data analysis and interpretation: Anneke Ullrich, Holger Schulz, Julia Messerer, Louise König

Manuscript writing: Anneke Ullrich, Karin Oechsle, Holger Schulz

Final approval of manuscript: Anneke Ullrich, Holger Schulz, Sven Goldbach, Wiebke Hollburg, Annette Rommel, Marten Müller, Denise Kirsch, Kathrin Kopplin-Foertsch, Julia Messerer, Louise König, Frank Schulz-Kindermann, Carsten Bokemeyer, Karin Oechsle

Acknowledgements

The support of all patients who participated in the present study was highly appreciated. We thank all staff members of the participating palliative care services for their dedicated and valuable work. Without them, conduct of this study would not have been possible. The
authors would like to thank Maren Wögens and Lisa K. Hackspiel for their research assistance.

References

1. Hodiamont F, Jünger S, Leidl R, Maier BO, Schildmann E, Bausewein C: Understanding complexity—the palliative care situation as a complex adaptive system. BMC Health Serv Res 2019, 19(1):157.

2. Hong J, Song Y, Liu J, Wang W, Wang W: Perception and fulfillment of cancer patients’ nursing professional social support needs: from the health care personnel point of view. Support Care Cancer 2014, 22(4):1049-1058.

3. Rohmoser A, Preisler M, Bär K, Letsch A, Goering U: Early integration of palliative/supportive cancer care—healthcare professionals’ perspectives on the support needs of cancer patients and their caregivers across the cancer treatment trajectory. Support Care Cancer 2017, 25(5):1621-1627.

4. Jordan K, Aapro M, Kaasa S, Ripamonti C, Scotté F, Strasser F, Young A, Bruera E, Herrstedt J, Keefe D: European Society for Medical Oncology (ESMO) position paper on supportive and palliative care. Ann Oncol 2018, 29(1):36-43.

5. Chung J, Kulkarni GS, Morash R, Matthew A, Papadakos J, Breau RH, Guttmann D, Bender J, Jones JM: Assessment of quality of life, information, and supportive care needs in patients with muscle and non-muscle invasive bladder cancer across the illness trajectory. Support Care Cancer 2019, 27(10):3877-3885.

6. Kuon J, Vogt J, Mehner A, Alt-Epping B, van Oorschot B, Sistermanns J, Ahlborn M, Ritterbusch U, Stevens S, Kahl C: Symptoms and needs of patients with advanced lung cancer: Early prevalence assessment. Oncol Res Treat 2019, 42(12):650-659.

7. Alt-Epping B, Seidel W, Vogt J, Mehner A, Thomas M, van Oorschot B, Wolff H, Schlephake H, Canis M, Dröge LH: Symptoms and Needs of Head and Neck Cancer Patients at Diagnosis of Incurability-Prevalences, Clinical Implications, and Feasibility of a Prospective Longitudinal Multicenter Cohort Study. Oncol Res Treat 2016, 39(4):186-191.

8. Boyes AW, Clinton-McHarg T, Waller AE, Steele A, D’Este CA, Sanson-Fisher RW: Prevalence and correlates of the unmet supportive care needs of individuals diagnosed with a haematological malignancy. Acta Oncol 2015, 54(4):507-514.

9. Bandeali S, des Ordons AR, Sinnarajah A: Comparing the physical, psychological, social, and spiritual needs of patients with non-cancer and cancer diagnoses in a tertiary palliative care setting. Palliat Support Care 2019, 17(1):30-38.

10. Walling AM, Tisnado D, Ettner SL, Asch SM, Dy SM, Pantoja P, Lee M, Ahluwalia SC, Schreibeis-Ham H, Malin J: Palliative care specialist consultation is associated with supportive care quality in advanced cancer. J Pain Symptom Manag 2016, 52(4):507-514.

11. Mesquita AC, Chaves ÉdCL, Barros GAMd: Spiritual needs of patients with cancer in palliative care: an integrative review. Curr Opin Support Palliat Care 2017, 11(4):334-340.

12. Mateo-Ortega D, Gómez-Batiste X, Maté J, Beas E, Ela S, Lasmarías C, Limonero JT: Effectiveness of psychosocial interventions in complex palliative care patients: a quasi-experimental, prospective, multicenter study. J Palliat Med 2018, 21(6):802-808.

13. Teo I, Krishnan A, Lee GL: Psychosocial interventions for advanced cancer patients: A systematic review. Psycho-Oncol 2019, 28(7):1394-1407.

14. Rego F, Gonçalves F, Moutinho S, Castro L, Nunes R: The influence of spirituality on decision-making in palliative care outpatients: a cross-sectional study. BMC Palliat Care 2020, 19(1):1-14.

15. Aoun SM, Breen LJ, Howting D: The support needs of terminally ill people living alone at home: a narrative review. Health Psychol Behav Med 2014, 2(1):951-969.

16. Reinke LF, Vig EK, Tartaglione EV, Rist P, Au DH: Symptom burden and palliative care needs among high-risk veterans with multimorbidity. J Pain Symptom Manag 2019, 57(5):880-889.

17. Spezialisierte ambulante Palliativversorgung

18. Jansky M, Lindena G, Nauck F: Stand der spezialisierten ambulanten Palliativversorgung (SAPV) in Deutschland–Verträge und Erfahrungen. Zeitschrift für Palliativmedizin 2011, 12(04):164-174.

19. Régincos P, Nau H, Hönnemann E-M: Spannungsfeld stationäre-nachstationäre Versorgung in Palliative Care. Zeitschrift für Palliativmedizin 2020, 20(01):21-26.

20. Götz H, Brähler E, Gansera L, Polze N, Köhler N: Psychological distress and quality of life of palliative cancer patients and their caring relatives during home care. Support Care Cancer 2014, 22(10):2775-2782.

21. Osse BH, Vernooj MJ, Schadé A, Grol RP: Towards a new clinical tool for needs assessment in the palliative care of cancer patients: the PNPC instrument. J Pain Symptom Manag 2004, 28(4):329-341.
22. Osse BH, Vernooij-Dassen MJ, Schadé E, Grol RP: A practical instrument to explore patients’ needs in palliative care: the Problems and Needs in Palliative Care questionnaire—short version. Palliat Med 2007, 21(5):391-399.

23. Roth AJ, Komblieth AB, Batel-Copel L, Peabody E, Scher HI, Holland JC: Rapid screening for psychologic distress in men with prostate carcinoma: a pilot study. Cancer 1998, 82(10):1904-1908.

24. Mehret A, Müller D, Lehmann C, Koch U: Die deutsche version des NCCN distress-thermometers: empirische Prüfung eines screening-instruments zur erfassung psychosozialer belastung bei krebspatienten. Zeitschrift für Psychiatrie Psychol und Psychotherapeutische Praxis 2006, 54(3):213-223.

25. Kroenke K, Spitzer RL, Williams JB, Löwe B: An ultra-brief screening scale for anxiety and depression: the PHQ–4. Psychosomatics 2009, 50(6):613-621.

26. Küttner S, Wüller J, Pastrana T: How much psychological distress is experienced at home by patients with palliative care needs in Germany? A cross-sectional study using the Distress Thermometer. Palliat Support Care 2017, 15(2):205.

27. Funk-Lawler R, Mundey KR: Understanding Distress Among Patients With Cancer Receiving Specialized, Supportive Care Services. Am J Hosp Palliat Care 2020:1049909120905780.

28. O’Callaghan CC, Georgousopoulou E, Seah D, Clayton JM, Kissane D, Michael N: Spirituality and religiosity in a palliative medicine population: mixed-methods study. BMJ Support Palliat Care 2020.

29. Smith GM, Calton BA, Rabow MW, Marks AK, Bischoff KE, Pantilat SZ, O’Riordan DL: Comparing the Palliative Care Needs of Patients Seen by Specialty Palliative Care Teams at Home Versus in Clinic. J Pain Symptom Manage 2020.

30. Chua GP, Pang GSY, Yee ACP, Neo PSH, Zhou S, Lim C, Wong YY, Qu DL, Pan FT, Yang GM: Supporting the patients with advanced cancer and their family caregivers: what are their palliative care needs? BMC Cancer 2020, 20(1):1-15.

31. Williams GR, Pisu M, Rocque GB, Williams CP, Taylor RA, Kwale EE, Bhatia S, Kenzik KM: Unmet social support needs among older adults with cancer. Cancer 2019, 125(3):473-481.

32. Moghaddam N, Coxon H, Nabarro S, Hardy B, Cox K: Unmet care needs in people living with advanced cancer: a systematic review. Support Care Cancer 2016, 24(8):3609-3622.

33. Wang T, Molassiotis A, Chung BPM, Tan J-Y: Unmet care needs of advanced cancer patients and their informal caregivers: a systematic review. BMC Palliat Care 2018, 17(1):96.

34. Rha SY, Lee HJ, Lee J: Unmet needs in the physical and daily living domain mediates the influence of symptom experience on the quality of life of gastric cancer patients. Support Care Cancer 2020, 28(3):1419-1431.

35. Janda M, Steginga S, Dunn J, Langbecker D, Walker D, Eakin E: Unmet supportive care needs and interest in services among patients with a brain tumour and their carers. Patient Educ Couns 2008, 71(2):251-258.

36. Seekatz B, Lukasczik M, Lühr M, Ehrmann K, Schuler M, Keßler AF, Schuler M, Mehnet A, Ernst J: Associations between dyadic coping and supportive care needs: findings from a study with hematologic cancer patients and their partners. Support Care Cancer 2017, 25(5):1445-1454.

37. Beesley VL, Price MA, Webb PM, O’Rourke P, Marquart L, Group AOCS, Investigators AOCSQoLS, Butow PN: Changes in supportive care needs after first-line treatment for ovarian cancer: identifying care priorities and risk factors for future unmet needs. Psycho-Oncol 2013, 22(7):1565-1571.

38. Stegmann ME, Geerse OP, Tange D, Richel C, Brom L, Engelen V, Duijts SF: Experiences and needs of patients with incurable cancer regarding advance care planning: results from a national cross-sectional survey. Support Care Cancer 2020:1-7.

39. Hess S, Stiel S, Hofmann S, Klein C, Lindena G, Ostgathe C: Trends in specialized palliative care for non-cancer patients in germany—Data from the national hospice and palliative care evaluation (hope). Eur J Intern Med 2014, 25(2):187-192.

40. Bostwick D, Wolf S, Samsa G, Bull J, Taylor Jr DH, Johnson KS, Kamal AH: Comparing the palliative care needs of those with cancer to those with common non-cancer serious illness. J Pain Symptom Manage 2017, 53(6):1079-1084. e1071.

41. Scaccabarozzi G, Amodio E, Riva L, Corli O, Maltoni M, Di Silvestre G, Turriani A, Morino P, Pellegrini G, Crippa M: Clinical Care Conditions and Needs of Palliative Care Patients from Five Italian Regions: Preliminary Data of the DEMETRA Project. In: Healthcare: 2020: Multidisciplinary Digital Publishing Institute; 2020: 221.
Figure 1
Recruitment process and patient cohort development

Supplementary Files
This is a list of supplementary files associated with this preprint. Click to download.

- SAUSPVSupportneedsBMCPCTables0521.docx
- SAUSPVSupportneedsBMCPCSupplementarymaterial0521.docx
- SAUSPVSupportneedsBMCPCSupplementarymaterial0521.docx