UNIVERSITÄTSKLINIKUM HAMBURG-EPPENDORF

II. Medizinische Klinik und Poliklinik, Onkologie, Hämatologie und
Knochenmarktransplantation mit Abteilung für Pneumologie
Bereich Palliativmedizin

Direktor der Klinik: Prof. Dr. med. Carsten Bokemeyer

Problems and Needs of Severely and Terminally Ill Patients at Initiation of Specialist Palliative Care in Hamburg

Dissertation

zur Erlangung des Grades eines Doktors der Medizin
an der Medizinischen Fakultät der Universität Hamburg.

vorgelegt von:

Julia Dorothea Messerer
aus Lörrach

Hamburg 2021

(wird von der Medizinischen Fakultät ausgefüllt)

Angenommen von der
Medizinischen Fakultät der Universität Hamburg am: 25.04.2022

Veröffentlicht mit Genehmigung der
Medizinischen Fakultät der Universität Hamburg.

Prüfungsausschuss, der/die Vorsitzende: Prof. Dr. Matthias Augustin

Prüfungsausschuss, zweite/r Gutachter/in: Prof. Dr. Karin Oechsle

Table of Contents

Working Hypothesis and Aim of the Present Study

It is not yet well evaluated, if conditions of specialist palliative care networks in Germany can adequately address the complex symptoms and problems of severely and terminally ill patients. Therefore, a prospective, longitudinal multicenter study on the development of symptoms, problems and needs of patients during specialist palliative care in Germany at the example of Hamburg was conducted.

In the present study, as part of this longitudinal study, questionnaires of patients at initiation of inpatient and outpatient specialist palliative care in Hamburg were analyzed. The main aim was to explore the presence and extent of physical, psychological, spiritual, and social problems, psychosocial distress, depression and anxiety, unmet needs as well as personal last wishes of these patients. Secondary questions concerned possible group differences regarding age, gender and especially type of care (inpatient or outpatient specialist palliative care) and the influence of common problems to psychosocial distress, depression, and anxiety. In the context of this large multicenter exploratory study, another objective was to identify reasons for ineligibility and non-participation of terminally ill patients, newly admitted to specialist palliative care in Hamburg.

1 Introduction

1.1 Goals and Principles of Palliative Care

"Everyone has the right to die in worthy conditions".[1] This is the first sentence of the Charter of the German Association for Palliative Care about the care for severely ill and dying persons in Germany (Deutsche Gesellschaft für Palliativmedizin et al., 2010). Such a claim is the aim of palliative care. The World Health Organization (WHO) defines palliative care as *"an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual"* (WHO, 2002). In addition, the European Association for Palliative Care (EAPC) emphasizes the interdisciplinary approach of palliative care and adds that palliative care *"affirms life and regards dying as a normal process; it neither hastens nor postpones death. It sets out to preserve the best possible quality of life until death"* (Radbruch and Payne, 2009). In their definition of palliative care, WHO and EAPC are guided by the total pain concept shaped by Cicely Saunders, the founder of modern palliative care in the early 1960s. Severely ill persons can hereby be assessed at four levels *"including not only physical symptoms but also mental distress and social or spiritual problems"* (Clark, 2007; Saunders, 2001). The combination of these elements results in an experience that is specific to the situation of each patient, as illustrated in Figure 1.

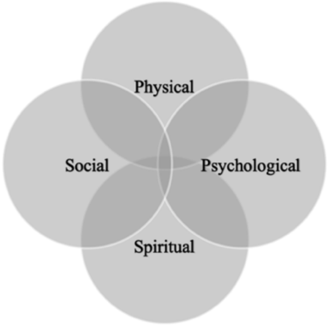

Figure 1: Total pain concept

(Adapted from S. Adler in Bausewein et al., 2018)

---

[1] Translations are done by the author (Julia Messerer), unless otherwise attributed.

A holistic perspective is achieved through care by a multiprofessional and interdisciplinary team consisting of specialized physicians, nurses, social workers, psychologists, pastoral workers, and various other professionals. Volunteers are included to bring aspects of regular life into care (Radbruch et al., 2010; Sepúlveda et al., 2002). This multiprofessional and interdisciplinary approach is based on a variety of symptoms of which severely and terminally ill patients suffer from generally. In addition to physical symptoms such as pain and weakness it also addresses psychological problems such as worries, as well as clinically relevant anxiety or depressive disorders (Miovic and Block, 2007; Teunissen et al., 2007). Severely and terminally ill patients are also confronted with social problems concerning occupation, financial issues, the need for care for themselves or the care of children, as well as with legal questions, for example in regard to living will and healthcare proxy (Mehnert and Schulz-Kindermann, 2016; Ventura et al., 2014).

Many of these aspects are not only burdensome for the patients themselves, but also affect their entire environment, especially their relatives. They may be increasingly affected by anxiety or depression and a compromised quality of life (Götze et al., 2014; Grov et al., 2005; Hudson et al., 2011; Wadhwa et al., 2013). Therefore, not only the needs of patients, but also those of their relatives, including those accompanying the patient's death, are considered in palliative care. Another goal of palliative care is to provide adequate care at the end of life in a place of choice also outside a hospital, as very often patients wish to be in their home environment (Radbruch et al., 2010; Sepúlveda et al., 2002).

Especially the evidence for the benefit of early integrated specialist palliative care has been growing for several years (Gaertner et al., 2017; Haun et al., 2017; Kavalieratos et al., 2016). It has been shown that an improvement in the quality of life also occurs when psychosocial care is already part of the conventional oncological treatment (Vanbutsele et al., 2018). A structured and regular symptom monitoring can improve quality of life and overall survival of patients with advanced cancer (Basch et al., 2017, 2016). Furthermore, efforts are being made to expand palliative care for patients with non-malignant diseases as in many European palliative care units up to 90% of patients suffer from oncologic diseases (Hess et al., 2014; Radbruch et al., 2011; Radbruch and Payne, 2009). Patients with non-malignant chronic diseases or dementia are more often cared for by general practitioners in general palliative care (Becka et al., 2014). At the moment in Germany, non-tumor patients are integrated very lately into specialist palliative care and at a much more advanced stage of disease than patients with oncologic diseases (Marcus J. P. Geist et al., 2018a; Markus J. P. Geist et al., 2018b).

1.2 Palliative Care in Germany

1.2.1 Structure of Palliative Care in Germany

In Germany, similar to worldwide structures, specialist palliative care (SPC) is differentiated from general palliative care, respectively in inpatient and outpatient settings. General palliative care refers to the provision of support by professionals without special training in palliative care, i.e., by general practitioners and nursing services. Accordingly, patients are cared for whose problems and symptoms are not so complex that they require specialist palliative care. General palliative care can therefore be described as the basis of palliative care (Leitlinienprogramm Onkologie et al., 2020; Radbruch et al., 2010).

SPC focuses on severely and terminally ill patients, who are affected by complex physical as well as psychosocial symptoms in such a way that care by a team of specialists with advanced training in palliative care and in specific structures is indicated. An SPC team should be multiprofessional, meaning it should be composed of members of at least three different occupational groups, physicians, nurses and further professionals, e.g., psychologists or social workers (Leitlinienprogramm Onkologie et al., 2020; Radbruch et al., 2010).

SPC is provided at home or in care facilities by specialist outpatient palliative care services (SAPV), in German: “Spezialisierte Ambulante Palliativversorgung” (Gemeinsamer Bundesausschuss, 2010), and in inpatient specialist palliative care units (PCU) (DIMDI, 2018). The German federal government has assumed in 2007 that about 10% of severely and terminally ill patients require SPC, while general palliative care should be adequate for 90% of severely and terminally ill patients (Hess et al., 2014; Radbruch and Payne, 2009). The structure of palliative care in Germany is summarized in Table 1.

Table 1: Structures of palliative care in Germany

(Adapted from K. Oechsle)

	General palliative care	Specialist palliative care
Outpatient	Family physicians, specialist physicians, nursing services	Specialist outpatient palliative care teams (SAPV)
Inpatient	Hospital wards	Palliative care units (PCU), inpatient hospices [a]

[a] Hospices can be attributed to inpatient and outpatient specialist palliative care.

The development of SPC in Germany is on the upswing. The Act to Improve Hospice and Palliative Care in Germany (“Hospiz- und Palliativgesetz”, HPG) became effective in 2015. It increased public and political attention to palliative care. Valid evaluations about the extent of improvement of palliative care in Germany are not yet possible. Especially within the federal states there is still a distinct heterogeneity of care infrastructures (Melching, 2019). For 2015, 1268 outpatient hospice services, 206 inpatient hospices, 289 PCUs in hospitals and 246 SAPV teams were listed (Deutsche Gesellschaft für Palliativmedizin, 2015; Prütz and Saß, 2017). In particular, the SAPV-teams are distributed unequally in the regions of Germany and nationwide care has not yet been achieved (Kratel, 2014; Prütz and Saß, 2017), especially in comparison with widespread emergency medicine (Wiese et al., 2010).

According to an international review of 2010, SPC seems to improve patient outcomes in pain and symptom control, anxiety and reduced hospital admission (Higginson and Evans, 2010). In another review the evidence for benefits from palliative care (specialist and general) remains sparse (Zimmermann et al., 2008). There are also critical voices calling for an expansion of general palliative care (Quill and Abernethy, 2013; Schneider et al., 2010). It can be emphasized that the purpose of SPC is to supplement primary care with an additional multiprofessional offer, that is aimed to the special needs of severely and terminally ill patients, but without replacing the primary care structure (Alt-Epping and Nauck, 2015). Though it is important to notice that some positive effects of SPC can be reached also through contact to SPC nurses (Vanbutsele et al., 2018).

1.2.2 Specialist Outpatient Palliative Care (SAPV) in Germany

The entitlement to Specialist Outpatient Palliative Care (SAPV) for persons with health insurance has been introduced in Germany in 2007 in §37b / §132d SGB V (Bundesgesetzblatt, 2007). It is stated that *"the specialist outpatient palliative care includes medical and nursing services including their coordination, especially for pain therapy and symptom control and aims to enable the care for insured persons in the familiar home environment"* (§37b (1), SGB V, translated by the author). Persons with health insurance are entitled to SAPV if they *"suffer from an incurable, progressive and far advanced disease that limits their life expectancy"* and require *"a particularly complex care"*. This need is present in case of insufficient general palliative care and the occurrence of complex symptoms *“whose treatment requires specific palliative care and/or palliative care knowledge and experience as well as an interdisciplinary approach, especially between* *physicians and nurses."* As an example, among others, especially severe pain is listed (Gemeinsamer Bundesausschuss, 2010). Meanwhile an international consensus was published on referral criteria for outpatient SPC (Hui et al., 2016).

The funding of twelve pilot projects to improve nationwide outpatient palliative care by the German Cancer Aid supported the establishment of SAPV in Germany (Schmidt-Wolf et al., 2013). Nonetheless, the SAPV in Germany was implemented very differently in various regions (Alt-Epping and Nauck, 2015). Full contractual coverage of SAPV could not yet be achieved in all federal states in 2015 (Richter-Kuhlmann, 2017)[2]. The frequency of initial SAPV prescription is strongly correlated to population density in different geographical regions in Germany (Gemeinsamer Bundesausschuss, 2018). When SAPV structures are well developed, most often in urban areas, general practitioners start to appreciate the relief provided by SAPV. Further, people increasingly demand SAPV services (Harms and Deckert, 2020).

It has repeatedly been shown that many seriously and terminally ill people wish to be enabled to die in their home environment, both in Germany and internationally. In a study in Germany, 94% of family members stated that their recently deceased relative would have liked their own home as place of death (Escobar Pinzon et al., 2011). There is a high level of satisfaction with palliative care in the home environment in Germany (Escobar Pinzón et al., 2010). According to a recent study, the situation of patients in SAPV in urban and rural areas in Germany is hardly different. Patients had similar care needs: 91% wanted symptom relief and 68% wanted to be able to stay at home. Regardless of the patient's place of residence, approximately 60% of SAPV patients died at home in their familiar environment (Heckel et al., 2015).

Numerous international studies have shown that outpatient SPC with multiprofessional teams in a home environment improves quality of life, symptom control, and patient satisfaction. The number of patients being able to die at home increases with outpatient SPC. It has also been shown that health care costs are reduced (Gomes et al., 2013). Also a German study demonstrated an improvement in the quality of life of patients and their relatives (Groh et al., 2013).

---

[2] The guideline of the GBA was based on a calculated nationwide demand of 330 SAPV teams, which each should be able to supply 250,000 inhabitants (Kratel, 2014).

1.2.3 Specialist Inpatient Palliative Care in Germany

A palliative care unit (PCU) is the main form of inpatient specialist palliative care and aims to improve the quality of life of patients with an incurable disease and limited life according to German guidelines (Leitlinienprogramm Onkologie et al., 2020). The requirement for the admission to a PCU is the need for hospital treatment by a multiprofessional specialist palliative care team. Possible criteria for admission are a complex symptom or problem burden, uncertainties regarding the therapeutic goal, elaborate medical or nursing care or insufficient SAPV (Gärtner et al., 2017; Leitlinienprogramm Onkologie et al., 2020). In addition, 'respite care' as a break for family members is made possible. Only few studies (quantitative and qualitative) compared the treatment in PCUs with usual care, therefore information on its effectiveness is limited. Two studies (almost 40 years old) describe a better symptom relief and an improved treatment satisfaction as well as less aggressive therapies and diagnostics (Greer et al., 1986; Kane et al., 1984; Leitlinienprogramm Onkologie et al., 2020). Cost reduction was also shown (Mercadante et al., 2008; Smith et al., 2003).

1.3 Experiences with Palliative Care (especially in Germany)

Germany was classified by the WHO in the highest development stage (4b) of the global atlas of palliative care in 2014, providing hospice and palliative care at an advanced level of integration into the health care system in general (Connor et al., 2014). The Hospice and Palliative Care Act (HPG) of 2015 can still be considered as a certainly well-intentioned and to a large extent also well-made law, which most importantly led to a significantly higher attention to hospice and palliative care. The current pitfalls can be attributed to the federal structure of the healthcare system, focusing on self-administration, and in some areas also to a lack of coordination and disagreement among the associations of service providers (Melching, 2019). As Lukas Radbruch, the former president of the German Society for Palliative Medicine, stated in 2019: *"In the past five years, the German Society for Palliative Medicine has therefore not only been concerned with the demand for more hospice and palliative care in Germany, but increasingly also with the question of the quality of this care"* (Radbruch, 2019). Therefore, it is important to notice, that *"adequate symptom treatment in palliative care patients can only be successful in a close dialogue between patients, their family caregivers, and the multidisciplinary palliative care team."* (Oechsle et al., 2013).

1.3.1 Symptoms and Problems of Severely and Terminally Ill Patients

Within the framework of the nationwide Hospice and Palliative Care Evaluation (HOPE) in Germany, data from 1616 inpatients and 414 outpatients (2007 to 2009) examining the self-assessed condition of severely and terminally ill patients during the course of SPC show the following results: At baseline weakness (78%), fatigue (63%) and pain (46%) were very common. For inpatients, a higher symptom burden was observed at the beginning of the treatment, which though improved more than in outpatients. While improvement in pain, fatigue, and weakness favored discharge from a palliative care unit, an increase in dyspnea, anxiety, and constipation resulted more frequently in ongoing hospitalization. In contrast, correlation between symptom burden and well-being was more pronounced in outpatients. In addition to weakness and fatigue, psychological and social burdens were also important (Jansky et al., 2012). In the general German population, almost all family members (88%) reported that their recently deceased relative had needed help with daily activities (Escobar Pinzón et al., 2012).

Apart from physical symptoms psychological issues are prevalent as well as already mentioned. One third of patients with cancer in Germany (32%) suffers from at least one mental disorder in the course of the disease (Mehnert et al., 2014). A review of German studies shows a point prevalence of 11% for affective disorders and of 14% for anxiety disorders (Vehling et al., 2012).[3] It is believed that these disorders occur more frequently in patients with incurable cancer, but currently there is no reliable data (Mehnert, 2015). An international literature review has shown a prevalence of 17% for depression in patients with cancer receiving palliative care, of 15% for adjustment disorders and of 10% for anxiety disorders. Combined diagnostics occurred in up to 29% of the patients. There were no significant differences compared to patients with cancer who did not receive palliative care (Mitchell et al., 2011).

There are indications in a German study that family members tend to overestimate the symptoms of critically and terminally ill patients, while physicians underestimate them. Therefore, treatment should take place in close collaboration between patients, relatives and a multidisciplinary team (Oechsle et al., 2013).

---

[3] Mitchell et al. point to a positive relationship between prevalence and age of study, which could account for the significant difference in the prevalence rates of depression compared to international literature (Mitchell et al., 2011; Vehling et al., 2012).

1.3.2 Needs and Wishes of Severely and Terminally Ill Patients

"Consciously putting patients' holistic needs at the center of everything is the cornerstone of supportive and palliative care" according to the European Society for Medical Oncology. So far, needs seem to be not adequately cared for in routine cancer assessment (Jordan et al., 2018). The German Society for Palliative Medicine defines need *"as a subjective individual claim or wish of a person or group of people or an experienced deficiency and stress state combined with the desire for remedy and satisfaction".* The direct interview of patients should be standard of care to evaluate present needs and a constant re-evaluation should take place to adapt the care during the course of treatment (Deutsche Gesellschaft für Palliativmedizin, 2016).

Three international reviews identified unmet needs across many areas (Moghaddam et al., 2016; Ventura et al., 2014; Wang et al., 2018). Especially needs in informational (30 to 55 %), psychological (18 to 42 %), physical (17 to 48 %) and functional (17 to 37 %) domains were commonly reported (Moghaddam et al., 2016). Among the most prevalent unmet items were emotional support (10 to 84%), fatigue (18 to 76%) and information about treatment (4 to 67%) (Wang et al., 2018). Additionally, effective communication with health-care professionals seems to be a widespread issue (Ventura et al., 2014).

Personal last wishes have not been addressed in studies in Germany so far. In one of the rare international studies concerning last wishes of advanced cancer patients, the most frequent last wishes were to be at peace with God, to have family members present, to be free from pain and not being a burden to one's family (Delgado-Guay et al., 2016).

1.3.3 Study Participation of Severely and Terminally Ill Patients

Very few studies have addressed the willingness and ability of severely and critically ill patients to participate in surveys, in Germany as well as internationally. It is often stated that recruitment to studies in palliative care is challenging, especially to randomized controlled trials (Grande and Todd, 2000) and to longitudinal studies (Steinhauser et al., 2006). The reasons for this include high burden of illness, high psychological distress and cognitive or communicative limitations (Ammari et al., 2015; Chaiviboontham, 2011; Gnass et al., 2016; Ransom et al., 2006). Gatekeeping by clinical staff also plays a role (Stone et al., 2013). In a German study, 16% of the patients were somnolent or comatose, 17% were affected by other cognitive and 14% by sensory impairments when admitted to SAPV (Heckel et al., 2015).

1.4 Open Questions concerning Palliative Care in Hamburg, Germany

The development of specialist palliative medical care structures in Germany (palliative care units and SAPV teams) was based on already known deficits in the treatment of severely and terminally ill patients. However, it has not been systematically investigated up to now whether these specialist forms of care in Germany adequately address the complex problems and needs. A decisive structural difference exists between inpatient and outpatient specialist palliative care in Germany: Specialist multiprofessional care including the care for relatives is provided in palliative care units in hospitals (DIMDI, 2018). In contrast, many SAPV teams are only bi-professional so far (physicians, nurses) because the services of other professional groups such as psychologists or therapists are not covered by health insurance (Alt-Epping and Nauck, 2015; Jansky et al., 2011). Such a contrast is particularly manifest as soon as the patients are discharged into the home care system when the psychological and psycho-oncological care which severely and terminally ill patients received at palliative care units (PCUs) is interrupted (Alt-Epping and Nauck, 2015; Régincos et al., 2020). This indicates a possible care deficit, in particular because it is already known that up to 50% of terminally ill patients in home settings suffer from mental disorders (Götze et al., 2014). Concepts need to be developed to guarantee the continuation of already existing inpatient therapies, such as psycho-oncology, physiotherapy, or music therapy, in the outpatient area as well. On a societal level, uniform and affordable solutions are needed to provide further care, based on an understanding of patients as individuals while being available to everyone on an equal basis (Régincos et al., 2020). As *"good palliative care takes account of the stress factors, the support needs of patients and relatives, and the available resources through advance care planning"* (Mehnert and Schulz-Kindermann, 2016).

Due to its nationwide first well-established supply network of inpatient and outpatient specialist palliative care, Hamburg can be regarded as a prime example for palliative care in Germany.

In this setting, it has been promising to explore the presence and extent of problems, psychosocial distress, unmet needs, anxiety, and depression of severely and terminally ill patients, who were newly admitted to inpatient and outpatient SPC. Special attention was paid to possible differences of symptom burden in regard to age, gender and type of care because especially patients referred to a PCU might have experienced a higher physical and psychological symptom burden compared to patients admitted to home-based care. A better understanding of the different symptoms and needs of patients based on age and gender can help to quickly assess needs of newly admitted patients and account for probable changes in care as patients get older. Furthermore, the prevalence of distress, anxiety and depression might be influenced by widespread problems which are experienced by severely and terminally ill patients at the beginning of SPC. The purpose of the present study was to lay a solid foundation for further investigations in order to see if problems and needs of these patients can be met by SPC under the current conditions in Germany.

A further aspect of the present study was to collect data about wishes of severely and terminally ill patients. It would help medical professionals to know what kind of wishes are expressed in order to better understand the expectations of severely and terminally ill patients particularly in the context of ‘informed decision making’ and ‘advance care planning’ in the future.

In the context of the present large multicenter exploratory study, it was interesting to identify reasons for ineligibility and non-participation of severely and terminally ill patients, newly admitted to specialist palliative care in Hamburg, aiming to better address studies to patients in SPC in the future.

2 Material and Methods

2.1 Study Design

The multicenter exploratory study presented here investigated the symptoms, problems and needs of severely and terminally ill patients newly admitted to specialist palliative care in Hamburg.

The present study was embedded in a prospective, longitudinal multicenter study in which the patients, the specialist palliative care teams and the relatives completed standardized questionnaires at different times during the course of the disease. It was funded by the German Cancer Aid. The aim was to investigate which problems and needs of severely and terminally ill patients can or cannot be adequately addressed despite the consistent implementation of specialist palliative care in the outpatient and inpatient network in Hamburg. Due to a lack of data in this topic, the design of an exploratory observational study was chosen to provide a better foundation for future research projects. Thus, the study can be considered as a developmental study aimed to improve existing services to meet the needs of severely and terminally ill patients more adequately in the future.

2.1.1 Setting and Data Collection

Patients were consecutively enrolled in six participating study centers in Hamburg (three SAPV-teams and three palliative care units) in a 12 months' period between June 2017 and July 2018 within a period of 72 hours after first admission to SPC.[4]

The survey was conducted using standardized self-report questionnaires by employees of the respective palliative care teams. It was ensured that interviews were associated with as little additional burden on patients as possible. For example, if desired, the survey could be integrated into the routine assessment in care. Assistance in completing the questionnaire upon request was possible. For storage, data were pseudonymized. Data had to be collected within the recruiting period.

---

[4] The initial timeframe was set to 48 hours from the initial contact with the patient and was extended to 72 hours after 6 months. Several palliative care teams had detected, that in the beginning some patients were excluded because of severe distress, who would have probably been able to participate within a recruiting time of 72 hours.

2.1.2 Participants (Inclusion and Exclusion Criteria)

All adult patients (over 18 years of age) suffering from an advanced, life-limiting illness (cancer and non-cancer), who were newly admitted to specialist palliative care, were eligible for study enrolment.

In case of an exclusion due to insufficient linguistic or cognitive abilities, the patients' imminent death or in case of a refusal to participate, a standardized form was completed for systematical documentation.[5] The patients were under no pressure to provide any reasons for non-participation in the research. Free-text answers were also possible.

The final criteria for exclusion and non-participation were:

- Limitations of the patient, e.g., cognitive impairments, so that completing the questionnaire would not be possible (medical or nursing assessment)
- Difficulties with the German language, so that completing the questionnaire would not be possible (medical or nursing assessment)
- Dying or deceased within recruitment phase
- No information possible within the recruitment phase
- No interest or refusal of participation

2.2 Measurements

The self-report questionnaire consists of German-language versions of three partial questionnaires: the NCCN Distress Thermometer – NCCN-DT (Mehnert et al., 2006; Roth et al., 1998), the Problem and Needs in the Palliative Care Questionnaire - Short Version - PNPC-sv (Osse et al., 2007) and the Patient Health Questionnaire Module 4 – PHQ-4 (Kroenke et al., 2009). The NCCN-DT and PHQ-4 are validated in German (Löwe et al., 2010; Mehnert et al., 2006), while the PNPC-sv has been translated into German and was tested in a small pilot sample. The German translation and the use of the PNPC-sv were kindly permitted by Prof. Myra Vernooij-Dassen of the University of Nijmegen, the Netherlands.

The DT and PNPC-sv were provided with a free text option, so that supplementation of the given items was possible for the respondents. In addition, the patient was asked the question *"Is there a special wish that you would like to be fulfilled? If yes, which one?"* with a free text option to express these wishes. Sociodemographic and care-related characteristics of the

---

[5] The non-participation form was adapted after 4 months to gather the reasons for exclusion more precisely.

patient were also recorded. This included age, gender, primary disease, nationality, religion, family status, children, grandchildren, school education, occupational status, profession, living environment, previous nursing situation, advance directives, and health insurance status.

2.2.1 NCCN-Distress-Thermometer

The NCCN-Distress-Thermometer (DT) is a screening tool developed by Roth et al. and was supplemented with a problem list by the National Comprehensive Cancer Network (NCCN) in the United States. It can be used to assess psychosocial distress in cancer patients (National Comprehensive Cancer Network, 2020; Roth et al., 1998). The DT measures the subjective distress over the past seven days on a 0 to 10 visual analogue scale in form of a thermometer. A score of four or higher indicates that the patient is distressed and needs further support. The accompanying problem list includes several items (rated yes and no) classified into different categories (practical, family, emotional, spiritual / religious, and physical). By listing the possible stressing problems, one obtains a scheme for the transfer of distressed patients to the appropriate professionals, e.g., psychologists or social workers. A score of less than four is considered as a mild level of distress, which does not require additional professional support (National Comprehensive Cancer Network, 2020).

The German version of the Distress-Thermometer, which was used in the present study, was established via a survey of 475 patients in oncological rehabilitation. Its problem list is based on a former version of the current DT-problem list including 36 items. For German-speaking countries, a score of 5 or higher in the DT can be recommended as a cut-off value. The German sample tended to have a higher sensitivity and correspondingly lower specificity values than those of international studies. The sensitivity of the German version was between 84% and 97% and the specificity between 41% and 47%, depending on the extent of distress. According to Mehnert et al. (2006), the low specificity values may indicate that *"because of the high sensitivity the scale tends to overestimate the prevalence of mental stress, leading to a high rate of false-positive decisions"* (Mehnert et al., 2006).

According to international literature, the optimal cut-off value is 4 (Donovan et al., 2014; Ma et al., 2014). A meta-analysis of 42 studies (14,808 patients) showed a pooled sensitivity of 81% (95% CI, 0.79–0.82) and a pooled specificity of 72% (95% CI, 0.71–0.72) at a cut-off score of 4 (Ma et al., 2014). Though, the optimal cut-off-value differs between countries and settings (Donovan et al., 2014). Regarding construct validity, the results of the validation study of the German version of the DT are consistent with the results of international studies:

significant correlations have been found between the distress thermometer and anxiety and depression variables of the Hospital Anxiety and Depression Scale (Donovan et al., 2014; Ma et al., 2014; Mehnert et al., 2006; Roth et al., 1998).

2.2.2 Problems and Needs in Palliative Care Questionnaire – Short Version

The Problems and Needs in Palliative Care Questionnaire – Short Version (PNPC-sv) is patient-centered and helps to identify problems that affect the quality of life and needs of care (Osse et al., 2007). Our version of the PNPC-sv asked for 23 aspects of daily activity, autonomy, social issues, psychological issues, spiritual issues, financial problems, and information needs, but not for physical symptoms. In addition, each patient is asked if he or she wants professional support in dealing with these problems. The potential answers are *"yes"*, *"a little"* and *"no"* regarding the question of whether the issues are a problem and *"yes, more than now"*, *"as much as now"* and *"no"* in relation to the desire for professional support. The items are considered a problem if the answers are *"yes"* or *"a little"*. The need for professional attention is assumed if the answer is *"yes, more than now"*. (Osse et al., 2004). In the implementation study refrain from care is determined in patients who do not want professional attention despite experiencing a specific problem. An unmet need is assumed, if more professional attention is wanted for an experienced problem (Osse et al., 2005).

The original 90-element PNPC Questionnaire was shortened to a short version with 33 elements (including 10 physical symptoms) to improve its practicality (Osse et al., 2007, 2004). According to Osse et al. (2007) *"the complete spectrum of dimensions that is essential in a holistic approach to palliative care"* was preserved. For the short version the selected items represented relevant problems for at least one in four patients. In regard to the reliability of the questionnaire, the internal consistency of the PNPC-sv dimensions to the problems and needs for care was usually sufficient, i.e. Cronbach's α higher than 0.70 (Osse et al., 2007). Generally accepted minimum standards for reliability coefficients are Cronbach's $\alpha > 0.70$ for group comparisons and Cronbach's $\alpha > 0.90 - 0.95$ for individual comparisons (Scientific Advisory Committee of the Medical Outcomes Trust, 2002). Therefore, it should be noted in the evaluation that the valuation of the dimensions cannot be used for individuals. However, they can be used for patient groups (Osse et al., 2004). The limitation of the application study is the sample, which was mainly composed of women with breast cancer, and is not representative for severely and terminally ill patients (Osse et al., 2007, 2005, 2004).

2.2.3 Patient Health Questionnaire – Module 4

The Patient Health Questionnaire – Module 4 (PHQ-4) is an ultra-short screening tool to identify patients who may be suffering from a depressive or anxiety disorder or both. It consists of a four-item scale composed of two depression items (PHQ-2) and two anxiety items (GAD-2) and uses a Likert scale. The PHQ-4 contains the core question, *"Over the last 2 weeks, how often have you been bothered by the following problems?"* It is asked for *"Little interest or pleasure in doing things"*, *"Feeling down, depressed, or hopeless"*, *"Feeling nervous, anxious, or on edge"* and *"Not being able to stop or control worrying"*. Responses are counted as 0 (*"not at all"*), 1 (*"several days"*), 2 (*"more than half the days"*) or 3 (*"nearly every day"*). Therefore, the total score is between zero and twelve. The PHQ-4 score can be categorized as a normal (0-2), mild (3-5), moderate (6-8) and severe (9-12) level for suspicion of a depression or anxiety order (Kroenke et al., 2009).

The PHQ-2 is a 2-item screening questionnaire as short-form of the Patient Health Questionnaire 9 (PHQ-9), which is based on the DSM-IV diagnostic criteria for major depressive disorder and has excellent reliability and validity (Kroenke et al., 2003; Löwe et al., 2004). Thus, Kroenke et al. (2003) found that a value of three or higher on the PHQ-2 scale from zero to six had a sensitivity of 83% and specificity of 90% for a major depression and a sensitivity of 62% and specificity of 95% for any depressive disorder (Kroenke et al., 2003).

The GAD-2 questionnaire is also a 2-item screening questionnaire as short-form of the General Anxiety Disorders Scale 7 (GAD-7), which is based on the DSM-IV diagnostic criteria for generalized anxiety disorders and also shows excellent reliability and validity (Kroenke et al., 2007; Spitzer et al., 2006). According to Kroenke et al. (2007), a score of three or greater on the GAD-2 scale from zero to six has a sensitivity of 65% and a specificity of 88% for any anxiety disorder and a sensitivity of 86% and a specificity of 83% for a generalized anxiety disorder (Kroenke et al., 2007).

The construct validity of the PHQ-4 was assessed by analysis of covariances: increasing PHQ-4 levels were correlated with increasing functional impairment (SF-20 functional status scale), days off sick and physician visits (Kroenke et al., 2009). According to Kroenke et al. (2009), the factor analysis confirmed two discrete factors (depression and anxiety), which accounted for 84% of the total variance.

The German version was established by means of a survey of 5030 participants from the general population (Löwe et al., 2010). Löwe et al. (2010) recommend reading PHQ-4 scores of six or more as *"yellow flags"* and PHQ-4 scores of nine or more as *"red flags"* for a possible depression or anxiety disorder. The individual calculation of the PHQ-2 depression and GAD-2 anxiety subscale scores should follow to examine whether a patient predominantly has depressive or anxiety disorders or both (Löwe et al., 2010). Löwe et al. (2010) also recommend, that PHQ-2 and GAD-2 values of three or greater can be evaluated as *"yellow flags"* and PHQ-2 and GAD-2 values of five or greater as *"red flags"*.

2.3 Statistical Analyses

The analysis of the collected data was done with IBM SPSS Statistics for Macintosh, Version 25.0. (NY: IBM Corp. Released 2017.) Categorical variables were described with absolute and relative frequencies. Continuous variables were described as means (M) plus/minus standard deviation (SD), median (Md), range (R) and in case of a score 95% confidence interval (CI).

2.3.1 Statistical Analysis of Evaluable Questionnaires

The first step was a descriptive analysis of the study sample of participants including sociodemographic and care related parameters as well as a comprehensive descriptive analysis of the various utilized questionnaires. The analysis of these instruments was based on the implementation studies (see 2.2.1/2.2.2/2.2.3 above). Additionally, severe psychosocial distress was defined (DT ≥8). An analysis of the DT-problem list and the PNPC-sv-questionnaire was done if 50% or more of the items on the list were completed by the patients. For data presentation, items were arranged within each dimension in descending order of frequency. The listed free-text answers were categorized. Scores for the PHQ-4, PHQ-2 and GAD-2 were calculated only if completely answered. Scores of DT and PHQ-4 were defined as continuous variables.

An inductive qualitative content analysis of patients wishes was done to identify key themes. Two researchers separately categorized the wishes, thereby main and subthemes were identified. These were discussed within the research team to reach consent in case of mismatching categorization. The utilized approach allowed measuring of the frequency of the identified different categories.

In a second step, the relationship between gender, age or type of care and the results was investigated by dichotomization of these three patient characteristics. Age was dichotomized in patients < 72 and ≥ 72 years old (median split), gender in male and female, and type of care in SAPV and PCU. Depending on the scale level of the considered target size different statistical tests were used. Differences between categorical variables (i.e., symptom prevalence) were evaluated with the chi-square test or Fisher's exact test. Differences between continuous variables (i.e., number of symptoms) were analyzed with t-tests (normally distributed data) and the Mann-Whitney U test (non-normally distributed data or markedly unequal group sizes). Due to multiple testing (n=3, i.e., age, gender, type of care) a Bonferroni correction was done, i.e., a p-value of $p<0.017$ was applied for rejection of null hypothesis (alpha error level $\alpha = 0.05/3 = 0.017$). Effect sizes were calculated according to Cohen (1992).

In addition, common problems of the PNPC-list, confirmed from more than 50% of the participating patients, were tested as potential predictors for severe distress (DT ≥8) and for suspicion of depression (PHQ-2) or anxiety disorders (GAD-2) with a stepwise logistic regression analysis (multivariate testing). Logistic regression analyses were based on complete data in the respective variables, therefore the sample size in the logistic regression analysis may be smaller than the sample size used to calculate individual variables, e.g., problem prevalence (list-wise deletion was used). All covariates which were statistically significant ($p<0.05$) on univariate analysis were tested for multicollinearity and if not correlated entered the logistic regression analysis (method: stepwise). Strengths of associations were expressed as odds ratios (OR) with 95% CI. To evaluate the goodness-of-fit of the logistic model we used Nagelkerke's pseudo R^2 with values >0.2 being considered acceptable.

2.3.2 Statistical Analysis of Exclusion and Non-Participation

The first step was a descriptive analysis of the overall sample of patients newly admitted to SPC during the study. A comparison was made between patients who had been excluded by the recruiting staff, who had refused or who had agreed to participate, in terms of age, gender and initial admission to the SAPV or PCU. Age was dichotomized in patients <75 and ≥75 years (median split), gender in male and female, and type of care in SAPV and PCU. If there was a significant general group difference ($\chi 2$ test, $p<0.05$), binominal tests were performed for a more accurate analysis, i.e., comparison to the frequency distribution in the overall study population. Due to multiple testing (n=3, i.e., age, gender, type of care) a Bonferroni correction was done, and the statistical tests were performed with 0.017% level of significance (see 2.3 above).

In a second step previously specified and free-text answers regarding reasons for study exclusion were categorized, followed by a descriptive analysis of the detected categories.

Again, these were compared in terms of age (median split), gender and type of care using $\chi2$ and binominal tests (for the approach see 2.3 above). Also, the reasons to refuse participation (free-text answers) were categorized and then a descriptive analysis of the detected categories was done.

2.4 Ethical Aspects

All patients were informed in detail about the methodology and objectives of the survey. The participants provided written informed consent before taking part in the study. Patients who did not take part in or rejected the study were also given adequate care and were constantly re-evaluated in terms of symptoms and distress. In doing so, needs (fulfilled or unfulfilled) were also addressed. The ethics committee of the General Medical Council of Hamburg, Germany approved the study protocol (reference number PV5062).

3 Results

3.1 Patient Recruitment and Characteristics

Overall, 1,713 patients were newly admitted to the specialist palliative care (SPC) of the six participating study centers in Hamburg in the 12 months period between June 2017 and July 2018.

Figure 2 presents a flow-chart of the sample development. At least one criterion of exclusion was present in 58% (n = 990) of the newly admitted patients. Of the 723 eligible patients, 39% (n = 280) declined to participate. Nonetheless, 61% (n = 443) of the eligible patients agreed to participate in the study. 16 patients failed to return the questionnaire; 2 patients withdrew their consent.

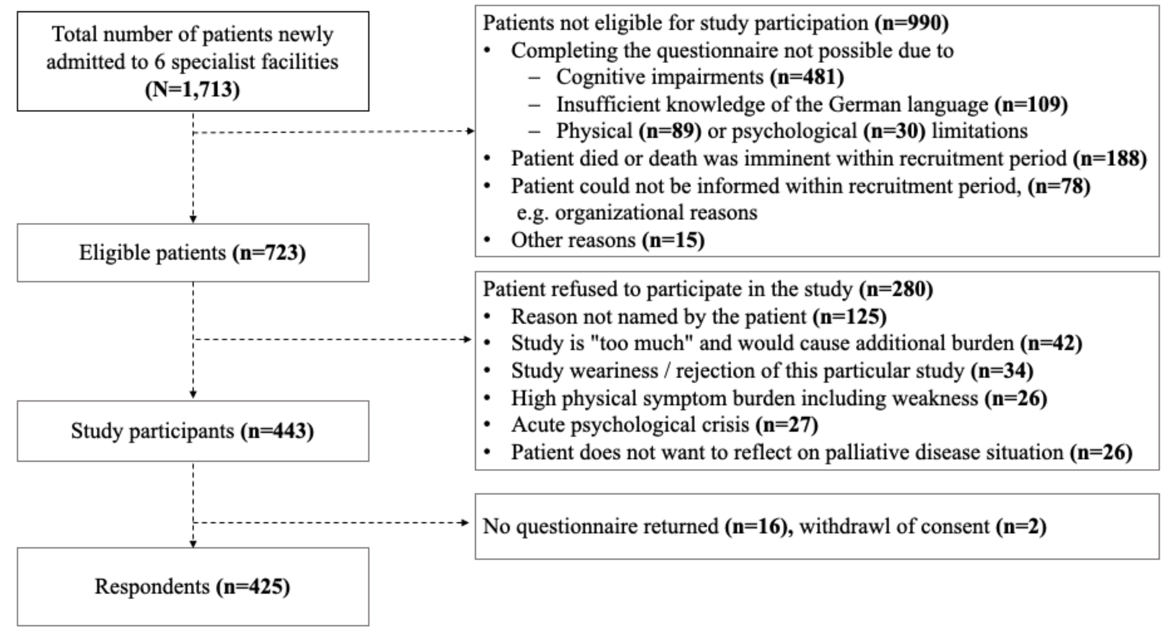

Figure 2: Recruitment process and sample development.

Data from Hamburg, 06/2017 to 07/2018. Abbreviations: N = number of study population, n = number of patients in respective categories.

A total of 425 patients responded to the questionnaire. Sociodemographic and care-related characteristics are shown in Table 2 and

Table 3. The mean age of the patients was 69.7 ± 12.5 years with the median at 72 years of age (range 26 to 96). About half of the patients were female (48%), half were male (52%). Two thirds of the patients were admitted to outpatient SPC (67%, n = 285) and one third to inpatient SPC (33%, n = 140). The majority of patients suffered from malignant diseases (92%, n = 389). The range of diagnoses was wide: urogenital and breast cancer (32%) was most common, followed by gastrointestinal cancer (25%) and cancer of the respiratory system (18%). More specified information on the primary diseases can be assessed in Appendix 1. After having discovered during the data analysis that central data concerning age, gender and underlying disease of the participating patients were often missing (Age: 9.2%, gender: 4.0%, underlying disease: 15.5% missing), these data were supplemented subsequently. Information on the occupational status of the participants can be found in Appendix 2.

Before being admitted to SPC, 58% (n = 243) of the patients lived at home, 17% (n = 71) were thereby supported from a nursing service, 7% (n = 28) stayed at a nursing home and 18% (n = 77) were in a hospital (data of 6 missing).

Overall, 28% (n = 118) of the patients needed support for completing the questionnaire. This happened more often at palliative care units, where half of the patients (46%, n = 65) had to be supported in contrast to 19% (n = 53) of the outpatients ($p < .001$). Age and gender did not differ (both $p \geq .017$).

Table 2: Sociodemographic characteristics of participating patients

Ñ=425	N	n	%
Age (M, SD)	425	69.7 (12.5)	
Gender	424		
Female		204	48.1
Male		220	51.9
School education [a]	414		
Low (≤9 years)		168	40.6
Intermediate (10 years)		117	28.3
High (12-13 years)		129	31.2
Occupation	411		
Retired		317	77.1
Employed/ self-employed		74	18.0
Currently unemployed/ other		20	4.9
Family status	424		
Married / life partnership		211	49.8
Divorced/ widowed		133	31.4
Single		80	18.9
Children	423		
Yes		302	71.4
No		121	28.6
Grandchildren	405		
Yes		201	49.6
No		204	50.4
Living environment	418		
Living alone		135	32.3
Living with family or family nearby		283	67.7
Nationality	412		
German		395	95.9
Other		17	4.1
Religion	409		
Protestant		190	46.5
Catholic		31	7.6
Other		14	3.4
None		174	42.5

[a] *School education: Low = secondary general school-leaving certificate or less, Intermediate = intermediate school-leaving certificate, High = university entrance qualification.*

Abbreviations: Ñ = number of patients included in analysis. N = total number of patients who completed the item, n = number of patients who confirmed the item, % = valid percent.

Table 3: Care-related characteristics of participating patients

Ñ=425	**N**	**n**	**%**
Admitted to SPC	425		
SAPV		285	67.1
PCU		140	32.9
Primary disease	425		
Urogenital and breast cancer		136	32.0
Gastrointestinal cancer		104	24.5
Cancer of the respiratory system		77	18.1
Other malignancies		72	16.9
Non-malignant		36	8.5
Previous nursing situation	405		
No nursing		78	19.3
By relatives		151	37.3
By nursing service		116	28.6
By nursing service and relatives		60	14.8
Advanced directives	425		
Living will		287	67.5
Healthcare proxy		275	64.7
Guardianship		22	5.2
None		86	20.2
Health insurance	425		
Statutory		356	83.8
Private		66	15.5
Supplementary		28	6.6
None		1	0.2

Abbreviations: Ñ= number of patients included in analysis. N = total number of patients who completed the item, n = number of patients who confirmed the item, SAPV = specialist outpatient palliative care, SPC = specialist palliative care, PCU = palliative care unit, % = valid percent.

3.2 Psychosocial Distress of Patients at Initiation of Specialist Palliative Care and Potential Reasons

Almost all participating patients (97%, n = 413) have reported valid scores in the NCCN-Distress-Thermometer. Most patients stated a score of five or higher and thus reached the cut-off value for clinically relevant distress (89%, n = 369). Half of the patients even had severe distress (53%, n = 217), they reported a score of eight or higher. The mean score was 7.2 (SD = 2.2, Md = 8.0, R = 0 to 10).

Even 98% (n = 417) of the patients provided information on at least half of the 36 items in the problem list of the DT. Table 4 shows the potential reasons for distress indicated in the DT-problem list. On average, 14.5 problems were reported (SD = 5.5, Md = 14.0, R = 0 to 29). The five most common problems were fatigue (92%), exercise / mobility (91%), pain (76%), food / nutrition (68%) and washing / getting dressed (67%). All five can be classified as physical problems. Half of the patients reported ten or more physical problems out of a total of 21 items (49%, n = 203). Three-quarters reported two or more emotional problems out of a total of six items (75%, n = 309). Among these, worries (64%), fears (62%) and sadness (62%) were most common. Almost one-fifth of the patients (19%, n = 79) mentioned two or more practical problems (five items in total). Here, problems with transportation (31%) and the housing situation (28%) were most common. Family problems and spiritual / religious issues (two items each) were affirmed only by 7 respective 9 % of the patients. Four percent (n = 16) of the patients mentioned at least one additional problem, among them other physical complaints were particularly frequent, e.g., *thirst*. One patient declared: *"A lot of things seem more exhausting than I expected."*

Psychosocial distress as well as patients' problems reported to cause distress were compared regarding potential differences in age, gender and type of care. Distress and the total amount of problems did not differ much between those different groups. Further data can be found in Appendix 3 and Appendix 4.

.

Table 4: Problems of severely and terminally ill patients at admission to specialist palliative care

Ñ = 417[a]	N	n	%		N	n	%
Practical problems				**Physical problems**			
Transportation	401	124	30.9	Fatigue	413	381	92.3
Housing	412	114	27.7	Getting around	413	374	90.6
Insurance/financial	408	45	11.0	Pain	417	318	76.3
Work/ school	413	20	4.8	Eating	402	274	68.2
Childcare	414	2	0.5	Bathing/ dressing	404	270	66.8
				Indigestion	411	260	63.3
Family problems				Breathing	406	233	57,4
Dealing with children	408	35	8.6	Sleep	409	231	56.5
Dealing with partner	414	32	7.7	Nausea	408	225	55.1
				Constipation	408	207	50.7
Emotional problems				Skin dry/ itchy	409	203	49,6
Worry	406	258	63.5	Memory/ concentration	409	200	48.9
Fears	405	250	61.7	Appearance	397	177	44.6
Sadness	405	250	61.7	Tingling in hands/feet	408	173	42.4
Loss of interest in usual activities	400	222	55.5	Feeling swollen	407	153	37.6
Nervousness	403	164	40.7	Changes in urination	407	147	36.1
Depression	397	133	33.5	Nose dry/ congested	406	143	35.2
				Sexual	388	109	28.1
Spiritual/religious concerns				Mouth sores	408	114	27,9
Loss of faith	383	33	8.6	Diarrhea	407	100	24.6
Relating to God	384	31	7.4	Fevers	410	37	9.0

Sorted in descending order within the categories. Tool: DT-problem list.

[a] *Included: 417 of 425 patients (98.1%), who completed at least 50% of the items indicated in the DT-problem list.*

Abbreviations: DT = Distress-Thermometer, Ñ = number of patients included in analysis, N = total number of patients who answered the item, n = number of patients who confirmed the item, % = valid percent.

Examining the individual problems mentioned in the DT-problem list, the following statistically significant differences were discovered. The reported relationships are all weak (r = 0.115 to 0.234) according to Cohen (1992). Further data is available in Appendix 5, Appendix 6, and Appendix 7.

Younger patients (<72 years) affirmed in contrast to older patients more often worries (71% vs. 58%; p = .009, r = 0.120), sadness (71% vs. 57%; p = .006, r = 0.130), and sexual problems (40 % vs. 19%; p < .001, r = 0.217). They also reported more problems in dealing with the partner (13% vs. 4%; p = .002, r = 0.149), and in the area of work / school (9% versus 1%; p < .001, r = 0.190). Women in contrast to men reported more problems regarding emotions: worries (70% vs. 57%; p = .007, r = 0.136), fears (69% vs. 54%; p = .002, r = 0.153), sadness (72% vs. 52 %; p < .001, r = 0.196), and nervousness (47% vs. 35%; p = .015). They also more often affirmed nausea (64% vs. 46%; p < .001, r = 0.186), and felt more swollen / bloated (44% vs. 32%; p = .001). In contrast, sexual problems (39% vs. 18%, p < .001), and fever (13% to 5%, p = .005, r = 0.231) were more prevalent in men. More outpatients than inpatients named problems with transportation (35% vs. 23%; p = .013, r = 0.124). The following physical symptoms were more prevalent in inpatients in contrast to outpatients: tingling in hands and feet (54% vs. 36%; p = .001, r = 0.169), feeling swollen / puffy (50% vs. 32%; p < .001, r = 0.174), dry / blocked nose (43% vs. 31%; p = .015, r = 0.122), and fever (14% vs. 7%; p = .015, r = 0.120).

To summarize, almost all patients (89 %) were distressed at initiation of SPC, half of the patients (53%) even severely. They suffered from 15 problems on average, the majority reported physical problems (up to 92%) and emotional problems (up to 64%). Problems concerning daily living (housing/ transportation) were mentioned by 30% of the patients. Family and spiritual problems were only named by 10% of the patients. Inpatients and outpatients at initiation of SPC only differed in the frequency of a few physical problems, but not in the amount of distress. Emotional problems were more prevalent in younger patients and women, sexual problems in younger patients and men.

3.3 Problems and Needs of Patients at Initiation of Specialist Palliative Care

Almost all participating patients (98%, n = 415) provided information on at least half of the items of the Problems and Needs in Palliative Care Questionnaire. Table 5 shows the five most frequent problems, needs for more attention, refrain from professional care, and unmet needs. A complete descriptive analysis of the PNPC-sv is displayed in Table 6, based on Osse (2005).

Twelve problems were mentioned by at least 50% of the patients. These relate to daily activities (3), autonomy (4), psychological issues (3), social issues (1) and spiritual issues (1). As the most common problem "personal transportation" was mentioned in the category of daily activities (88%). "Difficulties in continuing the usual activities" (90%) was the most common problem in the category of autonomy, "finding it difficult to talk about the disease because of not wanting to burden others" (54%) in the category of social issues, "fear of progression of the disease" (82%) in the category of psychological issues, and "difficulties to be of avail for others" (57%) in the category of spiritual issues. Social issues concerning the communication with others were mentioned by a third of the patients as a problem (20 to 36%).

The three most common problems are also reflected in the three needs for more attention that were most often reported: "personal transportation", "doing light housework" and "difficulties in continuing the usual activities". All three concern daily activities. Overall, 84 to 90% of the patients experienced those problems and 40 to 44% wanted more professional attention for these topics. In contrast, 18 to 27% of the patients did not want any professional support for those problems. Needs for more professional attention were mentioned by 11 to 44% of the patients depending on the item. Apart from daily activities also difficulties in concern to autonomy (24 to 39%) and in coping with the unpredictably of the future (34%) were frequently named.

Table 5: The five most common problems, needs for more attention, unmet needs, and refrain from professional care

	Problems	%
1.	Difficulties in continuing the usual activities	90.2
2.	Personal transportation (cycling, driving a car, using public transportation, etc.)	88.2
3.	Doing light housework	83.7
4.	Being dependent on others	83.5
5.	Fear of progression of the disease	82.0
	Needs for more attention	%
1.	Personal transportation (cycling, driving a car, using public transportation, etc.)	43.8
2.	Doing light housework	41.4
3.	Difficulties in continuing the usual activities	39.3
4.	Difficulty coping with the unpredictability of the future	33.8
5.	Insufficient information, e.g., about the disease and its treatment, aids and agencies that can provide help	32.7
	Refrain from professional care [a]	%
1.	Personal transportation (cycling, driving a car, using public transportation, etc.)	27.4
2.	Being dependent on others	27.0
3.	Difficulties in continuing the usual activities	24.0
4.	Difficulties to be of avail for others	22.0
5.	Difficulties to give tasks out of hands	20.8
	Unmet needs [b]	%
1.	Insufficient information, e.g., about the disease and its treatment, aids and agencies that can provide help	83.3
2.	Extra expenditures because of the disease	61.9
3.	Loss of income because of the disease	60.0
4.	Difficulties in finding someone to talk to (confidant)	55.9
5.	Difficulties concerning the meaning of death	53.1

Tool: PNPC-sv.

[a] *Refrain from care: the percentage of the population (Ñ = 415) who do not want any professional attention despite experiencing the topic as a problem (Yes + Somewhat)*

[b] *Unmet needs: the percentage of patients who need more professional attention for a topic as a percentage of those patients who actually experience that specific problem (Yes + Somewhat)*

Abbreviations: Ñ = number of patients included in analysis, % = valid percent, PNPC-sv = Problems and Needs in Palliative Care Questionnaire – Short Version.

There were also other topics for which patients specifically did not want professional attention despite experiencing the topic as a problem (refrain from care). Being dependent on others (autonomy) was among the most common refrain from care as well as other aspects of autonomy. A majority of the patients (84%) confirmed dependence on others as a problem, one third (32%) opted for more professional attention. In contrast, 27% of the patients did not want any professional support. Interestingly, for difficulties in communication (social problems) only 5 to 14% of the patients did not want professional support, when experiencing these problems.

Of those patients who mentioned a problem at least a third up to even 80% considered their needs in this regard as not adequately cared for and wanted more professional support. The most common unmet need in the category of daily activities was “doing light housework” (49%), in the category of autonomy “experiencing loss of control over one’s life” (44%), in the category of social issues “difficulties in finding someone to talk to” (56%), in the category of psychological issues: “difficulty in coping with the unpredictability of the future” (46%), and in the category of spiritual issues “difficulties concerning the meaning of death” (53%). In particular, despite only 34% reporting insufficient information about the disease and possible care options as a problem, a large majority of those (83%) wished for this particular problem to be taken care of. Also, if financial problems were reported (extra expenditures 30%; loss of income 17%) people hoped for more support (60%). For these last topics only very few patients (1 to 4%) did not want any professional attention.

At least one additional problem and need for care was mentioned by 7% of the patients (n = 28), four of the patients mentioned two additional problems. Despite being already part of the original questionnaire the need for more information was frequently mentioned in the free-text field as well. One patient declared: *"I was at many doctors, and nobody recommended a palliative team at an early stage."* The need for more general support and the improvement of communication between patients and doctors, but also between the different health care services, were also mentioned several times.

Table 6: Problems and needs of patients at admission to specialist palliative care

Ñ=415 [a]	Is this a problem?				Do you want professional attention for this?				Refrain from care [b]		Unmet needs in patient with the problem [c]	
		Yes	Some what	No		Yes, more	As much as now	No				
	N	n (%)			N	n (%)			N	n (%)	N	n (%)
Daily activities												
Personal transportation (cycling, driving a car, using public transportation, etc.)	408	316 (77.5%)	50 (12.3%)	42 (10.3%)	390	171 (43.8%)	82 (21.0%)	137 (35.1%)	387	106 (27.4%)	352	167 (47.4%)
Doing light housework (tidying up, etc.)	405	288 (71.1%)	51 (12.6%)	66 (16.3%)	391	162 (41.4%)	100 (25.6%)	129 (33.0%)	385	71 (18.4%)	323	158 (48.9%)
Body care, washing, dressing, or toilet	409	190 (46.5%)	100 (24.4%)	119 (29.1%)	386	121 (31.3%)	126 (32.6%)	129 (36.0%)	382	52 (13.6%)	283	118 (41.7%)
Autonomy:												
Difficulties in continuing the usual activities	408	299 (73.3%)	69 (16.9%)	40/ (9.8%)	382	150 (39.3%)	111 (29.1%)	121 (31.7%)	379	91 (24.0%)	346	147 (42.5%)
Being dependent on others	411	260 (63.3%)	83 (20.2%)	68 (16.5%)	382	123 (32.2%)	101 (26.4%)	158 (41.4%)	378	102 (27.0%)	321	121 (37.7%)
Experiencing loss of control over one’s life	404	169 (41.8%)	96 (23.8%)	139 (34.4%)	368	114 (31.0%)	74 (20.1%)	180 (48.9%)	364	74 (20.3%)	253	110 (43.5%)
Difficulties to give tasks out of hands	404	169 (41.8%)	57 (14.1%)	178 (44.1%)	365	85 (23.3%)	69 (18.9%)	211 (57.8%)	361	75 (20.8%)	214	78 (36.4%)
Social issues												
Finding it difficult to talk about the disease, because of not wanting to burden others	402	149 (37.1%)	68 (16.9%)	185 (46.0%)	363	96 (26.4%)	46 (12.7%)	221 (60.9%)	358	69 (19.3%)	205	95 (46.3%)

Ñ=415 [a]	Is this a problem?				Do you want professional attention for this?				Refrain from care [b]		Unmet needs in patient with the problem [c]	
		Yes	Somewhat	No		Yes, more	As much as now	No				
	N	n (%)			N	n (%)			N	n (%)	N	n (%)
Finding others not receptive to talking about the disease	408	66 (16.2%)	84 (20.2%)	258 (63.2%)	358	54 (15.1%)	50 (14.0%)	254 (70.9%)	354	48 (13.6%)	140	52 (37.1%)
Difficulties in finding someone to talk to (confidant)	409	97 (23.7%)	47 (11.5%)	265 (64.8%)	359	78 (21.7%)	40 (11.1%)	241 (67.1%)	355	27 (7.6%)	136	76 (55.9%)
Difficulties in talking about the disease with life companion	407	62 (15.2%)	63 (15.5%)	282 (69.3%)	361	59 (16.3%)	40 (11.1%)	262 (72.6%)	357	35 (9.8%)	117	55 (47.0%)
Problems in relationship with life companion	406	35 (8.6%)	48 (11.8%)	323 (79.6%)	354	38 (10.7%)	33 (9.3%)	283 (79.6%)	350	18 (5.1%)	80	35 (43.8%)
Psychological issues:												
Fear of progression of the disease	411	271 (65.9%)	66 (16.1%)	74 (18.0%)	-	-	-	-	-	-	-	-
Difficulty coping with the unpredictability of the future	403	194 (48.1%)	89 (22.1%)	120 (29.8%)	373	126 (33.8%)	89 (23.9%)	158 (42.4%)	367	63 (17.2%)	265	123 (46.4%)
Difficulties to show emotions	410	118 (28.8%)	93 (22.7%)	199 (48.5%)	373	65 (17.4%)	70 (18.8%)	238 (63.8%)	371	70 (18.9%)	199	65 (32.7%)
Depressed mood	410	92 (22.4%)	92 (22.4%)	226 (55.1%)	365	75 (20.5%)	63 (17.3%)	227 (62.2%)	362	39 (10.8%)	171	74 (43.3%)
Spiritual issues:												
Difficulties to be of avail for others	404	168 (41.6%)	63 (15.6%)	173 (42.8%)	358	85 (23.7%)	55 (15.4%)	218 (60.9%)	355	78 (22.0%)	214	85 (39.7%)
Difficulties to accept the disease	411	149 (36.3%)	81 (19.7%)	181 (44.0%)	358	104 (29.1%)	63 (17.6%)	191 (53.4%)	356	52 (14.6%)	208	103 (49.5%)

Ñ=415 [a]	Is this a problem?				Do you want professional attention for this?				Refrain from care [b]		Unmet needs in patient with the problem [c]	
		Yes	Some what	No		Yes, more	As much as now	No				
	N	n (%)			N	n (%)			N	n (%)	N	n (%)
Difficulties to be engaged usefully	408	133 (32.6%)	69 (16.9%)	206 (50.5%)	362	78 (21.5%)	59 (16.3%)	225 (62.2%)	360	56 (15.6%)	186	78 (41.9%)
Difficulties concerning the meaning of death	404	106 (26.2%)	86 (21.3%)	212 (52.5%)	355	94 (26.5%)	50 (14.1%)	211 (59.4%)	353	44 (12.5%)	175	93 (53.1%)
Financial problems:												
Extra expenditures because of the disease	407	80 (19.7%)	42 (10.3%)	285 (70.0%)	351	66 (18.8%)	35 (10.0%)	250 (71.2%)	349	13 (3.7%)	105	65 (61.9%)
Loss of income because of the disease.	405	50 (12.3%)	20 (4.9%)	335 (82.7%)	352	41 (11.6%)	24 (6.8%)	287 (81.5%)	350	13 (3.7%)	65	39 (60.0%)
Need of information:												
Insufficient information, e.g., about the disease and its treatment, aids and agencies that can provide help	404	89 (22.0%)	49 (12.1%)	266 (65.8%)	355	116 (32.7%)	42 (11.8%)	266 (65.8%)	350	5 (1.4%)	132	110 (83.3%)

Sorted in descending order of problems within the categories. Tool: PNPC-sv.

[a] *Included: 417 patients (98.1%), who completed at least 50% of the items in the PNPC-sv.*

[b] *Refrain from care: the percentage of the population (Ñ = 415) that does not want any professional attention despite experiencing the topic as a problem (Yes + Somewhat)*

[c] *Unmet needs: the percentage of patients who need more professional attention for a topic as a percentage of those patients who actually experience that specific problem (Yes + Somewhat). n varies in this column.*

Abbreviations: Ñ = number of patients included in analysis. N = total number of patients who completed the item, n = number of patients who confirmed the item, % = valid percent. PNPC-sv, Problems and Needs in Palliative Care Questionnaire – Short Version.

Problems and unmet needs were also compared in terms of age, gender, and type of care. Few statistically significant differences between the groups were detected. These are shown in Table 7 and Table 8. The relationships were all weak (r = 0.111 to 0.279) according to Cohen (1992). Further data can be found in Appendix 8 to Appendix 13.

Table 7: Problems in terms of age, gender, and type of care at admission to specialist palliative care

	N	[n/N (%)]	[n/N (%)]	*p*	*Phi*
Age		**<72 yrs.**	**≥72 yrs.**		
Experiencing loss of control over one's life	404	142/199 (71.4%)	123/205 (60.0%)	*0.016*	*0.122*
Depressed mood	410	103/201 (51.2%)	81/209 (38.8%)	*0.011*	*0.126*
Extra expenditures because of the disease	407	73/201 (36.3%)	49/206 (23.8%)	*0.006*	*0.139*
Loss of income because of the disease.	405	56/201 (27.9%)	14/204 (6.9%)	*<0.001*	*0.279*
Gender		**Male**	**Female**		
Difficulties to give tasks out of hands	403	104/209 (49.8%)	121/194 (62.4%)	*0.011*	*0.127*
Difficulties in finding someone to talk to (confidant)	408	87/215 (40.5%)	56/193 (29.0%)	*0.016*	*0.128*
SPC		**SAPV**	**PCU**		
Personal transportation (cycling, driving a car, using public transportation, etc.)	408	252/272 (92.6%)	114/136 (83.8%)	*0.006*	*0.140*
Doing light housework (tidying up, etc.)	405	236/270 (87.4%)	103/135 (76.3%)	*0.004*	*0.141*
Difficulties to accept the disease	411	165/274 (60.2%)	65/137 (47.4%)	*0.014*	*0.111*
Insufficient information, e.g., about the disease and its treatment, aids and agencies that can provide help	404	104/268 (38.8%)	34/136 (25.0%)	*0.006*	*0.131*
Loss of income because of the disease.	405	38/271 (14.0%)	32/134 (23.9%)	*0.014*	*0.121*

Sorted in descending order within the first category. Tool: PNPC-sv. Adjusted p-value p < 0.017 after Bonferroni correction due to multiple testing. Chi^2*-tests.*

Abbreviations: N = total number of patients who answered the item, n= number of patients who confirmed the item, SAPV = specialist outpatient palliative care, SPC = specialist palliative care, PCU = palliative care unit, % = valid percent, p = probability of type I error (chi^2*-test), Phi = effect size.*

Table 8: Group comparison of unmet needs in terms of age, gender and type of care

	N	[n/N (%)]	[n/N (%)]	*p*[a]	*Phi*
SPC		**SAPV**	**PCU**		
Difficulties to accept the disease	208	87/154 (56.5%)	16/54 (29.6%)	*0.001*	*0.236*
Body care, washing, dressing, or toilet	283	95/191 (49.7%)	23/92 (25.0%)	*<0.001*	*0.235*
Finding others not receptive to talking about the disease	140	43/98 (43.9%)	9/42 (21.4%)	*0.012*	*0.213*

Sorted in descending order within the first category. Tool: PNPC-sv. Adjusted p-value p < 0.017 after Bonferroni correction due to multiple testing. Chi^2*-tests.*
Abbreviations: N = total number of patients who answered the item, n= number of patients who confirmed the item, SAPV = specialist outpatient palliative care, SPC = specialist palliative care, PCU = palliative care unit, % = valid percent, p = probability of type I error (chi^2*-test), Phi = effect size.*

Overall, severely and terminally ill patients experienced several problems and needs outside the physical area at initiation of SPC. Especially aspects concerning daily activities were often mentioned, but also difficulties with autonomy and psychological issues played an important role. Unmet needs were experienced from at least one out of three patients with a specific problem and concern, in particular information and financial problems. They were also often experienced in the other areas like daily activities, autonomy, social, psychological, and spiritual issues. Only few differences in regard to type of care, age and gender were detected.

3.4 Depression and Anxiety in Patients at Initiation of Specialist Palliative Care

Almost all participants completed both items of the PHQ-2 (96%, n = 409). Both items of the GAD-2 were completed by 98% of the participating patients (n = 415) and 95% of the participants (n = 405) completed all four items of the PHQ-4. Figure 3 shows the percentage of patients being suspect for depression or anxiety. Half of the patients were suspect of depression (PHQ-2 ≥ 3, 52%, n = 211) and almost 40% were suspect of an anxiety disorder (GAD-2 ≥ 3, 38%, n = 156), referred to as yellow flags. Looking especially at a high probability for a depression or anxiety disorder, 27% (n = 110) in the PHQ-2 and 19% (n = 77) in the GAD-2 reached the cut-off-value (≥ 5), referred to as red flags as a subset of yellow flags. Table 9 contains more information regarding the characteristics of the items. The mean score of the PHQ-4 was 5.3 (SD = 3.7), of the PHQ-2: 3.0 (SD = 2.0) and of the GAD-2: 2.4 (SD = 2.0).

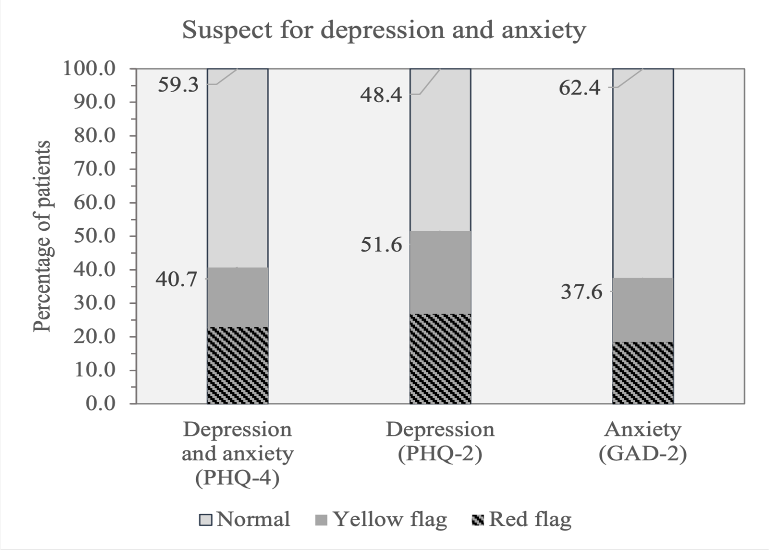

Figure 3: Depression and anxiety suspected in patients newly admitted to specialist palliative care

Tool: PHQ-4. Red flags = subset of yellow flags. Yellow flags: PHQ-4 ≥ 6, PHQ-2 ≥ 3, GAD-2 ≥ 3. Red flags: PHQ-4 ≥ 9, PHQ-2 ≥ 5, GAD-2 ≥ 5. Abbreviations: GAD-2 = General Anxiety Disorders - Scale 2, PHQ-2 = Patient Health Questionnaire - Module 4, PHQ-4 = Patient Health Questionnaire - Module 4.

Table 9: Characteristics of the PHQ-4 in patients newly admitted to specialist palliative care

	Ñ [a]	M	95% CI	Md	SD	R
PHQ-4	405					
Total scale score		5.3	5.0-5.7	4.0	3.7	0-12
PHQ-2 (depression items)	409					
Little interest or pleasure in doing things		1.64	1.53-1.75	1.0	1.11	0-3
Feeling down, depressed, or hopeless		1.34	1.24-1.45	1.0	1.17	0-3
PHQ-2 sum score		3.0	2.8-3.2	3.0	2.0	0-6
GAD-2 (anxiety items)	415					
Feeling nervous, anxious, or on edge		1.20	1.10-1.31	1.0	1.07	0-3
Not being able to stop or control worrying		1.16	1.06-1.27	1.0	1.12	0-3
GAD-2 sum score		2.4	2.2-2.6	2.0	2.0	0-6

[a] Calculated if complete answers were available (PHQ-4: 95.3%, PHQ-2: 96.2%, GAD-2: 97.6%)

Abbreviations: CI= Confidence interval, GAD-2 = General Anxiety Disorders - Scale 2, M = mean, Md = Median, Ñ= number of patients included in analysis, PHQ-2 = Patient Health Questionnaire - Module 2, PHQ-4 = Patient Health Questionnaire - Module 4, R = Range, SD = standard deviation.

For patients admitted to outpatient SPC, rates were 50% for depression and 39% for anxiety, for inpatients 55% respective 35%, again without showing group differences (all p ≥. 017). In regard to age and gender no differences could be detected either (all p ≥. 017). For illustration see Figure 4. See Appendix 14 for further results.

Overall, almost half of severely and terminally ill patients (41%, PHQ-4 ≥ 6) were suspect of a depression or anxiety disorder at initiation of SPC. Half of these patients (50%) were even highly suspect of depression or anxiety. This was valid in inpatients as well in outpatients. Also, no frequency differences regarding gender and age could be found.

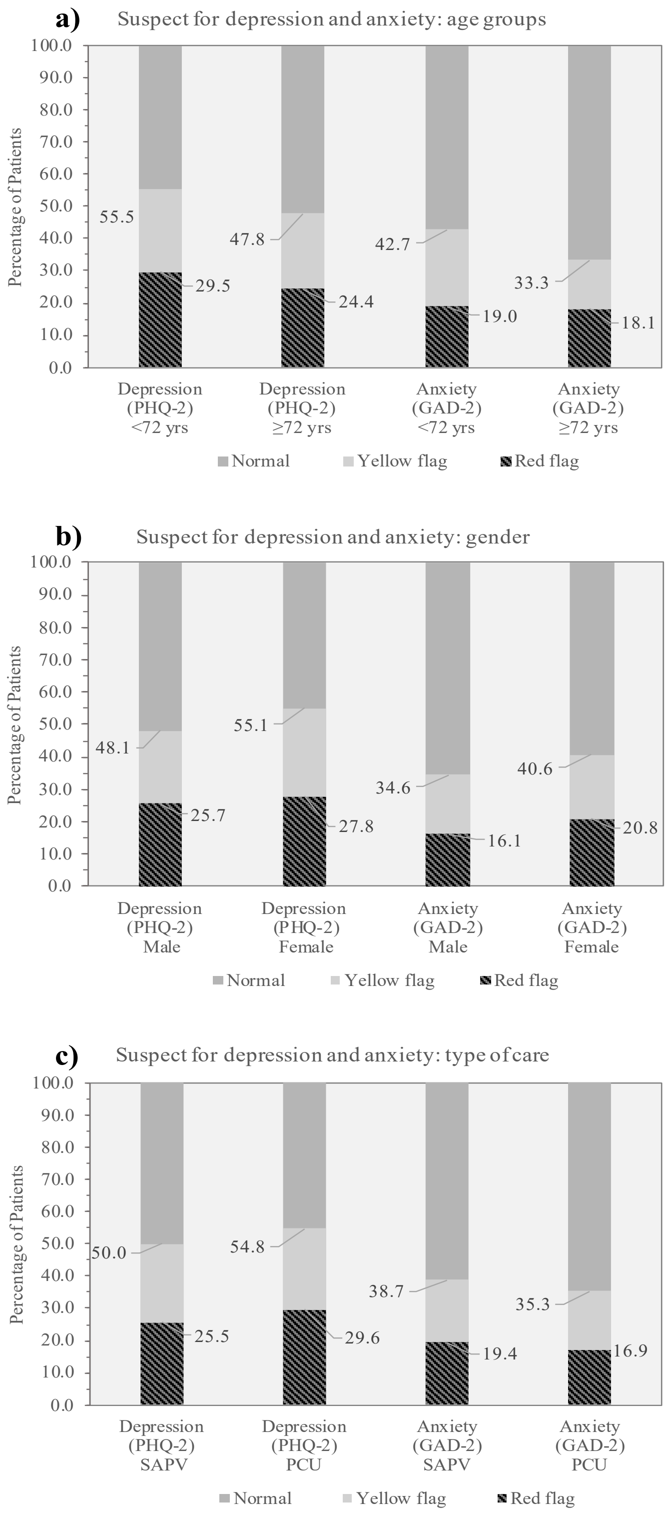

Figure 4: Group comparison depression and anxiety in terms of a) age b) gender and c) type of care

Tool: PHQ-4. Red flags = subset of yellow flags. Yellow flags: PHQ-4 ≥ 6, PHQ-2 ≥ 3, GAD-2 ≥ 3. Red flags: PHQ-4 ≥ 9, PHQ-2 ≥ 5, GAD-2 ≥ 5. Abbreviations: GAD-2 = General Anxiety Disorders - Scale 2, PCU = palliative care unit, PHQ-2 = Patient Health Questionnaire -Module 4, PHQ-4 = Patient Health Questionnaire -Module 4, SAPV = specialist outpatient palliative care.

3.5 Problems as Predictors for Higher Psychosocial Distress, Depression, and Anxiety of Patients at Initiation of Specialist Palliative Care

The problems of the PNPC-sv reported in more than 50% of the patients were tested as possible influencing factors for having higher distress (DT ≥ 8) or being suspect of depression (PHQ-2 ≥ 3) and anxiety (GAD-2 ≥ 3). The results of the univariate and consequently multivariate testing using a stepwise logistic regression analysis are shown in Table 10, Table 11 and Table 12.

Multivariate testing revealed the following problems as a predictor for higher distress (DT ≥ 8): difficulties with body care, washing, dressing, or toilet ($ß = 0.503$, $p = .039$) and experiencing loss of control over one's life ($ß = 0.919$, $p < 0.001$); stepwise logistic regression analysis, Nagelkerke's R2 = 0.087 (see Table 10).

Being suspect of depression (PHQ-2 ≥ 3) could be predicted by difficulties in continuing the usual activities ($ß = 1.142$, $p = 0.013$), the difficulty coping with the unpredictability of the future ($ß = 0.544$, $p = 0.046$), difficulties to be of avail for others ($ß = 0.864$, $p < .001$) and difficulties to give tasks out of hands ($ß = 0.635$, $p = 0.007$); stepwise logistic regression analysis, Nagelkerke's R2 = 0.206 (see Table 11).

Being suspect of anxiety (GAD-2 ≥ 3) could be predicted by difficulties with doing light housework ($ß = 0.872$, $p = .022$), the difficulty in coping with the unpredictability of the future ($ß = 0.967$, $p = .005$), experiencing loss of control over one's life ($ß = 1.133$, $p < .001$), difficulties to be of avail for others ($ß = 0.971$, $p < .001$), difficulties to accept the disease ($ß = 0.756$, $p = .006$) and difficulties to give tasks out of hands ($ß = 0.523$, $p = .046$); stepwise logistic regression analysis, Nagelkerke's R2 = 0.345 (see Table 12).

Table 10: Problems associated with being severely distressed (DT ≥ 8) at admission to specialist palliative care

	Univariate logistic regression for DT ≥ 8				**Multivariate logistic regression for DT ≥ 8**			
Problems PNPC (%)	β	S.E.	OR (95%CI)	p	β	S.E.	OR (95%CI)	p
Difficulties in continuing the usual activities (90.2)	.961	.352	2.614 (1.312-5.208)	**.006**	-	-	-	-
Personal transportation (88.2)	.698	.343	2.010 (1.026-3.938)	**.042**	-	-	-	-
Doing light housework (83.7)	.615	.276	1.850 (1.077-3.178)	**.026**	-	-	-	-
Being dependent of others (83.5)	.130	.263	1.139 (.681-1.907)	.620	+	+	+	+
Fear of progression of the disease (82.0)	.463	.255	1.589 (.964-2.622)	.070	+	+	+	+
Body care (70.9)	.599	.222	1.819 (1.177-2.813)	**.007**	.503	.244	1.654 (1.025-2.667)	**.039**
Difficulty coping with the unpredictability of the future (70.2)	.688	.221	1.991 (1.291-3.069)	**.002**	-	-	-	-
Experiencing loss of control over one's life (65.6)	.996	.217	2.707 (1.769-4.140)	**<.001**	.919	.231	2.506 (1.593-3.943)	**<.001**
Difficulties to be of avail for others (57.2)	.508	.204	1.663 (1.115-2.479)	**.013**	-	-	-	-
Difficulties to accept the disease (56.0)	.372	.200	1.450 (.980-2.147)	.063	+	+	+	+
Difficulties to give tasks out of hands (55.9)	.483	.203	1.620 (1.088-2.413)	**.018**	-	-	-	-
Finding it difficult to talk about the disease, because of not wanting to burden others (54.0)	.351	.202	1.420 (.956-2.110)	.082	+	+	+	+
Difficulties to show emotions (51.5)	.098	.199	1.103 (.747-1.628)	.622	+	+	+	+

Multivariate binary logistic regression analysis: N = 357 of 425 possible patients.

Nagelkerke's pseudo R^2 = .206

Reference groups: dependent variable - DT < 8; independent variables - having the mentioned problem vs. not having the mentioned problem.

- excluded from the model by backward selection

+ not included in multivariable regression model due to result of univariate analysis

Abbreviations: β = unstandardized regression coefficient, CI = 95% confidence interval, DT = distress thermometer, OR = odds ratio for independent variables, % = valid percent, p = probability of type I error, SE = standard error.

Table 11: Problems associated with being suspect for depression (PHQ-2 $\geq$3) at admission to specialist palliative care

	Univariate logistic regression for PHQ-2 $\geq$ 3				**Multivariate logistic regression for PHQ-2 $\geq$ 3**			
Problems PNPC (%)	β	SE	OR (95%CI)	p	β	SE.	OR (95%CI)	p
Difficulties in continuing the usual activities (90.2)	1.442	.393	4.231 (1.958-9.143)	**<.001**	1.142	.460	3.134 (1.271-7.729)	**.013**
Personal transportation (88.2)	.694	.341	2.002 (1.026-3.905)	**.042**	-	-	-	-
Doing light housework (83.7)	.899	.283	2.456 (1.409-4.281)	**.002**	-	-	-	-
Being dependent on others (83.5)	.929	.282	2.533 (1.457-4.404)	**.001**	-	-	-	-
Fear of progression of the disease (82.0)	.803	.268	2.232 (1.320-3.775)	**.003**	-	-	-	-
Body care (70.9)	.745	.225	2.107 (1.357-3.272)	**.001**	.432	.262	1.540 (.921-2.577)	.100
Difficulty coping with the unpredictability of the future (70.2)	.961	.227	2.614 (1.675-4.081)	**<.001**	.533	.267	1.704 (1.009-2.877)	**.046**
Experiencing loss of control over one's life (65.6)	1.154	.222	3.172 (2.053-4.901)	**<.001**	-	-	-	-
Difficulties to be of avail for others (57.2)	1.163	.211	3.198 (2.116-4.833)	**<.001**	.864	.240	2.372 (1.483-3.794)	**<.001**
Difficulties to accept the disease (56.0)	.731	.203	2.078 (1.395-3.095)	**<.001**	-	-	-	-
Difficulties to give tasks out of hands (55.9)	.960	.208	2.612 (1.737-3.925)	**<.001**	.635	.237	1.886 (1.186-3.000)	**.007**
Finding it difficult to talk about the disease, because of not wanting to burden others (54.0)	.796	.206	2.216 (1.480-3.317)	**<.001**	-	-	-	-
Difficulties to show emotions (51.5)	.584	.201	1.794 (1.210-2.660)	**.004**	-	-	-	-

Multivariate binary logistic regression analysis: N =357 of 425 possible patients.

Nagelkerke's pseudo $R^2 = .206$

Reference groups: dependent variable - PHQ-2 < 3.; independent variables - having the mentioned problem vs not having the mentioned problem.

- excluded from the model by backward selection

Abbreviations: ß = unstandardized regression coefficient, CI = 95% confidence interval, OR = odds ratio for independent variables, % = valid percent, p = probability of type I error, PHQ-2 = Patient Health-Questionnaire, SE = standard error.

Table 12: Problems associated with being suspect for anxiety (GAD-2 ≥3) at admission to specialist palliative care

	Univariate logistic regression for GAD-2 ≥ 3				**Multivariate logistic regression for GAD-2 ≥ 3**			
Problems PNPC (%)	β	S.E.	OR (95%CI)	p	β	S.E.	OR (95%CI)	p
Difficulties in continuing the usual activities (90.2)	1.372	.454	3.942 (1.618-9.607)	**.003**	-	-	-	-
Personal transportation (88.2)	1.037	.407	2.820 (1.270-6.265)	**.011**	-	-	-	-
Doing light housework (83.7)	1.176	.337	3.241 (1.673-6.276)	**<.001**	.872	.382	2.392 (1.131-5.059)	**.022**
Being dependent of others (83.5)	1.490	.359	4.439 (2.198-8.966)	**<.001**	-	-	-	-
Fear of progression of the disease (82.0)	1.278	.324	3.591 (1.903-6.776)	**<.001**	-	-	-	-
Body care (70.9)	.959	.249	2.610 (1.602-4.252)	**<.001**	-	-	-	-
Difficulty coping with the unpredictability of the future (70.2)	1.832	.294	6.246 (3.513-11.103)	**<.001**	.967	.345	2.629 (1.336-5.175)	**.005**
Experiencing loss of control over one's life (65.6)	1.735	.267	5.667 (3.359-9.559)	**<.001**	1.133	.300	3.104 (1.723-5.591)	**<.001**
Difficulties to be of avail for others (57.2)	1.549	.234	4.705 (2.975-7.443)	**<.001**	.971	.269	2.639 (1.559-4.469)	**<.001**
Difficulties to accept the disease (56.0)	1.451	.227	4.269 (2.738-6.656)	**<.001**	.756	.275	2.130 (1.243-3.650)	**.006**
Difficulties to give tasks out of hands (55.9)	.928	.217	2.530 (1.653-3.871)	**<.001**	.523	.262	1.687 (1.010-2.818)	**.046**
Finding it difficult to talk about the disease, because of not wanting to burden others (54.0)	.901	.215	2.462 (1.615-3.753)	**<.001**	-	-	-	-
Difficulties to show emotions (51.5)	1.157	.214	3.180 (2.091-4.837)	**<.001**	-	-	-	-

Multivariate binary logistic regression analysis: N = 357 of 425 possible patients.

Nagelkerke's pseudo $R^2 = .206$

Reference groups: dependent variable - GAD-2 < 3; independent variables - having the mentioned problem vs not having the mentioned problem.

- excluded from the model by backward selection

Abbreviations: β = unstandardized regression coefficient, CI = 95% confidence interval, GAD-2 = General Anxiety Disorders - Scale 2, OR = odds ratio for independent variables, % = valid percent, p = probability of type I error, SE = standard error.

3.6 Personal Last Wishes of Patients at Initiation of Specialist Palliative Care

Table 13 shows the themes and example quotes of personal last wishes. The question "Is there a special wish that you would like to fulfill?" was answered by 85% of the participating patients (n = 361). Two-thirds of these patients mentioned at least one wish (67%, n = 243). Among them were 12 patients who mentioned two wishes and two patients who mentioned three wishes.

Eight main themes were identified through a qualitative content analysis. Desires related to travel were hereby most frequently mentioned (31%), followed by desires for beneficial or challenging activities (18%), for a longer life or healing (17%), for a better quality of life (15%), and for spending more time with family and friends (14%). In addition, patients wished to experience conditions for "good dying" (6%), wished to turn back time (3%), and to get their affairs organized (2%). Three percent of the wishes were too vague and could not be attributed to one of the categories.

A different overarching theme could also be attributed to the expressed wishes. Many wishes seemed realistic for fulfilment, e.g., experiences such as *"ice cream"* and *"to see the sea once more"* or related to unfinished business such as travel destinations (*"back home to Italy"*) or life goals (*"to see my grandchildren once again"*). To spend time together with family and friends related often to travel and activities: *"to once travel with my son to London"* and *"going to the cinema with the family"*. In other wishes hope and dreams were expressed: *"a miracle should happen, so that I recover" or "with a sailing boat across the Atlantic"*.

Overall, 78% of the inpatients (n=96) confirmed a wish in contrast to just 62% of the outpatients (n = 147); *p* = .002. The patients did not differ in regard to age and gender (see Appendix 15).

Table 13: Personal last wishes articulated by severely and terminally ill patients

Main theme (n / %) [a]	**Subthemes** (n / %) [a]	Example quotes
Travel (75 / 30.9%)	**Travel & holiday** (51 / 21%)	*to tour the world, to travel to a nice place, Danube cruise*
	To the sea (15 / 6.2%)	*to see the sea once more, just go to the sea*
	Special places/ home (9 / 3.7%)	*back home to Italy, once again to Wesselburen*
Activities (43 / 17.7%)	**Pleasant** (36 / 14.8%)	*long forest walk, to dance at a festival, ice cream with whipped cream*
	Daring (7 / 2.9%)	*to jump out of a plane, with a sailing boat across the Atlantic*
Health & Life (40 / 16.5%)	**Recover, cure** (28 / 11.5%)	*a miracle should happen, so that I recover; to defeat the disease, cure*
	Live (longer) (12 / 4.9%)	*to live longer, I'm still needed; it would be nice, if I could live a little bit longer; gain of time*
Quality of life (37 / 15.2%)	**Be more mobile** (16 / 6.6%)	*be able to walk, to buy a new car and be able to drive, more freedom of movement*
	Place of living/ dying (at home) (8 / 3.3%)	*back home as soon as possible, never again to the hospital*
	Painlessness (6 / 2.5%)	*continue to live without pain, to have no more pain and become more active*
	Other (6 / 2.5%)	*no further aggravation, independence*
Family & Friends (35 / 14.4%)	**To spend time together** (11 / 4.5%)	*going to the cinema with the family, once again enjoying a great Mediterranean meal and a wonderful wine in a community round, to still spent much more time with the children*
	To see loved ones once more (11 / 4.5%)	*to see my grandchildren once again, to visit my family at the Cap Verde islands*
	Travel together (8 / 3.3%)	*to once travel with my son to London, a cruise with my wife*
	Witness special events (5 / 2.1%)	*to witness the wedding of my daughter, to witness the birth of a friend's baby*
Dying „well“ (14 / 5.8%)		*to come home and be at home with my family until the end of my life, to reach the end of life calmly, peacefully, and quickly; transfer to a hospice, no suffering before death*
Turning back time (6 / 2.5%)		*to be 60 again without worries, to turn back time*
Getting affairs organized (4 / 1.6%)		*that the children get along again and make peace, become debt-free (financially)*
Other wishes (6 / 2.5%)		*secret, my wish is unfulfillable*

Categorized in main- and subthemes revealed by qualitative content analysis. n = 243.

[a] Multiples answers possible; number / percentage of patients, who mentioned at least one personal last wish referring to this category.

Abbreviations: n = number of patients, % = valid percent.

3.7 Excluded and Non-Participating Patients

3.7.1 Characteristics of all Patients Newly Admitted to Specialist Palliative Care

Figure 5 shows characteristics of all patients (N = 1,713), who were newly admitted to SPC between June 2017 and July 2018. The mean age was 72.5 ± 13.9 years with the median at 75 years (r = 19 to 103). Half of all patients (50%, n = 863) were female and half were male (50%, n = 847). About half of all patients were admitted to outpatient SPC (48%, n = 821) and about half to inpatient SPC (52%, n = 874).

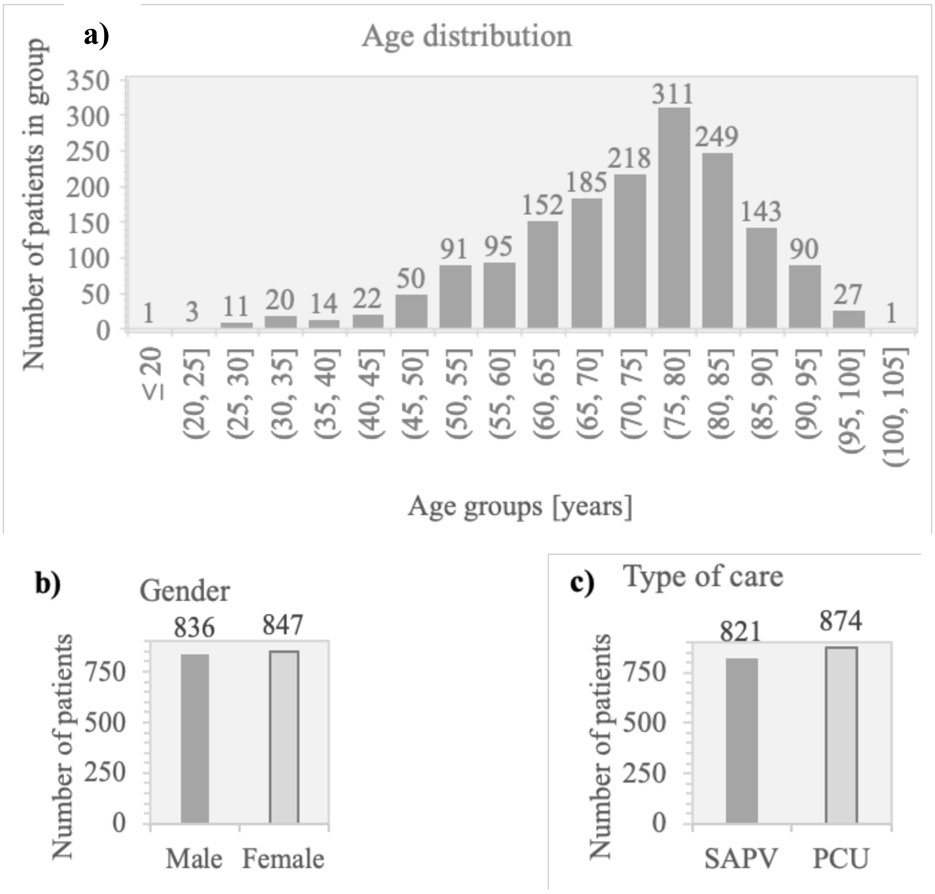

Figure 5: Characteristics of 1.713 patients newly admitted to specialist palliative care in Hamburg a) age distribution b) gender c) type of care

Data from June 2017 to July 2018. Data available: a) age distribution: N = 1683 b) gender: N = 1683 c) type of care: N = 1695. Abbreviations: N = data available, PCU = palliative care unit, SAPV = specialist outpatient palliative care.

3.7.2 Characteristics of Excluded and Non-Participating Patients

Patients who were excluded due to meeting at least one exclusion criterion were generally older than the overall average (58% ≥75 years, n = 575, p < .001) and more often admitted to inpatient SPC (60%, n = 597, p < .001). In contrast, the remaining participants were younger than overall average (61% <75 years, n = 260, p < .001) and more often admitted to outpatient SPC (67%, n = 285, p < .001). The non-participants did not differ from the distribution of characteristics present in the overall study population. See Figure 6 for the characteristics (age, gender, type of care). A detailed table of the analysis can be seen in Appendix 16.

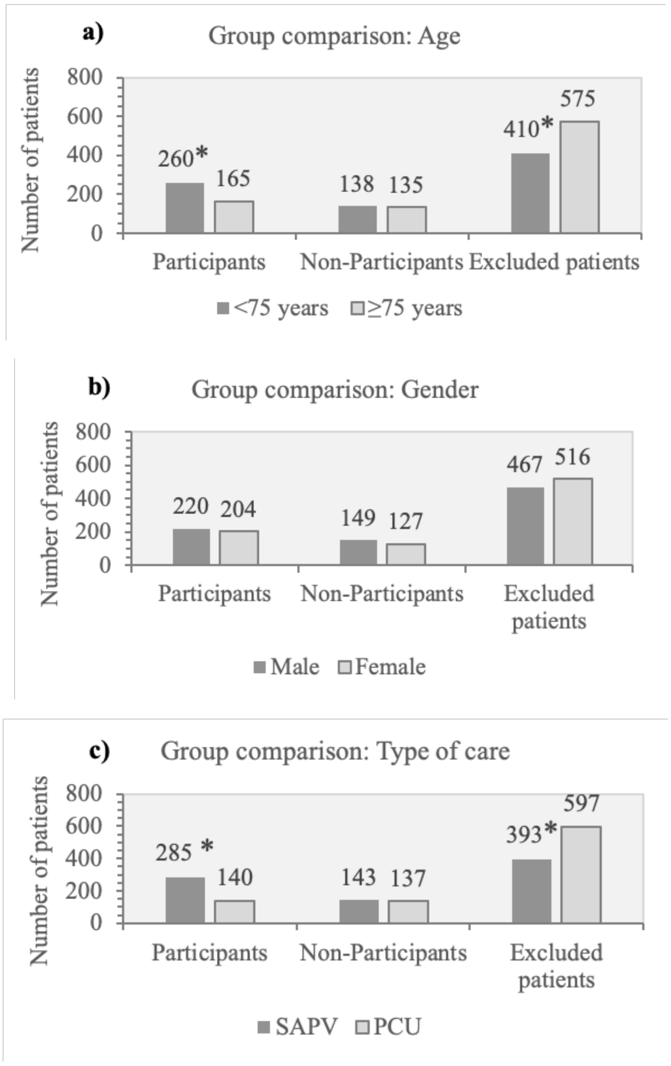

Figure 6: Group comparison of potential study-participants in terms of a) age distribution b) gender and c) type of care.

Data from June 2017 to July 2018. Data available: a) age distribution: N = 1683 b) gender: N = 1683 c) type of care: N = 1695. * $p < .017$, adjusted p-value after Bonferroni correction due to multiple testing. Abbreviations: N=data available, p = probability of type I error (binominal test to distribution in overall study population), PCU = palliative care unit, SAPV = specialist outpatient palliative care.

3.7.3 Reasons for Exclusion of the Study

The reasons for exclusion are displayed in Figure 7. At least one criterion of exclusion was present in 58% (n = 990) of the newly admitted patients. Half of the patients (49%, n = 481) could not complete the survey due to cognitive impairments. One-fifth of the patients (19%, n = 188) were excluded because they were in the final dying phase or died within the recruitment period. Table 14 provides a more detailed analysis of some individual reasons for exclusion.

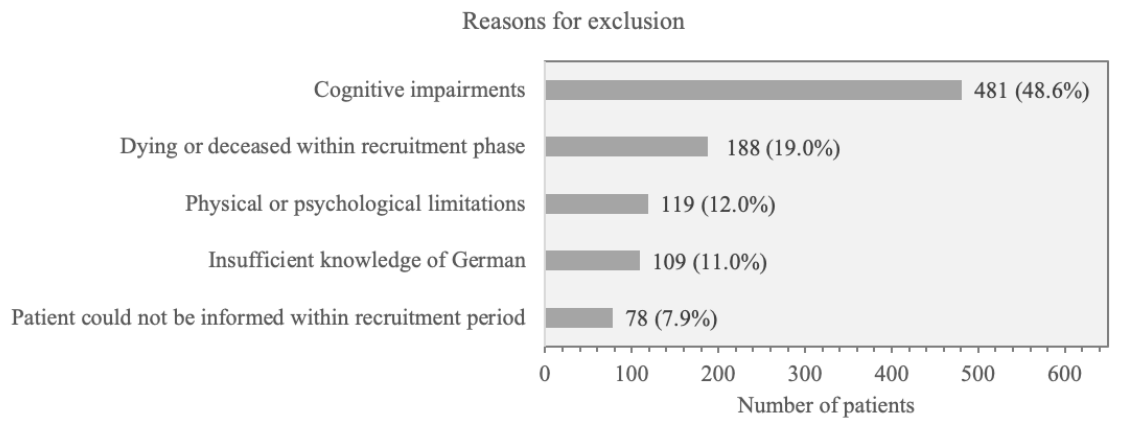

Figure 7: Reasons for exclusion of the study

990 of 1713 patients had to be excluded. Data from June 2017 to July 2018. Reasons are listed according to frequency. 1.5% (n = 15) could not be attributed to a category.

Table 14: Detailed breakdown of individual reasons for exclusion of the study

	n	%
Cognitive impairments (N=481)		
Dementia	101	21.0
Delirium	22	4.6
Sedation	103	21.4
Disorientation	50	10.4
Brain tumor/ Brain metastases	44	9.1
Not differentiated	161	33.5
Physical or psychological limitations (N=119)		
Reduced general condition, weakness, high symptom burden	66	55.5
No speech ability / deafness	17	14.3
Psychological stress too high	30	25.2
Other	6	5.0
Patient could not be informed within recruitment period (N=78)		
Organizational reasons (patient not encountered)	56	71.8
Admission / transfer / discharge within recruitment period	14	17.9
Not known	8	10.3

Abbreviations: N = number of patients in category, n = number of patients in subcategory, % = valid percent.

The main reasons for exclusion from the study were compared in terms of age, gender and type of care (see Figure 9). Patients who were dying or died within the recruitment period were older than average (68% ≥ 75 yrs., n = 127, p = .007), and to a large extent admitted to inpatient SPC (80%, n = 151, p < .001). Patients who were excluded due to problems with the German language were younger than average (70% < 75 yrs., n = 76, p < .001) and more often admitted to outpatient SPC (61%, n = 66, p < .001). Exclusion because of the patient not being informed within the recruitment period was more common at the participating PCUs (74%, n = 58, p = .007). Other analyses of the frequency distributions did not show group differences (all p ≥ .017). See Appendix 17 for a more detailed statistical analysis.

3.7.4 Reasons for Non-Participation

Of the 723 eligible patients, 39% (n = 280) declined to participate. For characteristics see Figure 6 above. The majority of these patients (45%, n = 125) did not want to specify their reason for refusing to participate. The mentioned reasons can be assessed in Figure 8 and include in particular indications to high distress in severely and terminally ill patients.

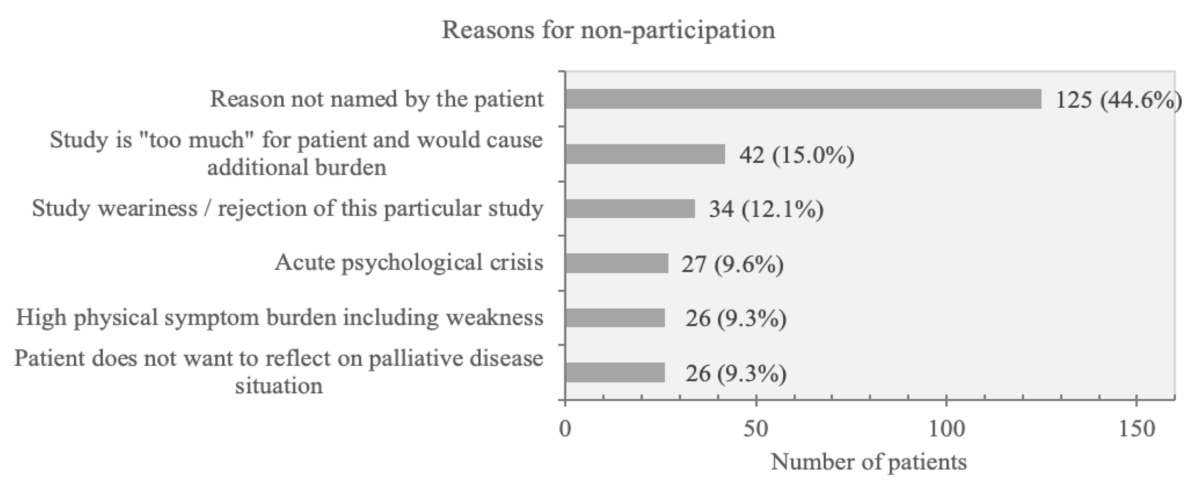

Figure 8: Reasons for non-participation at the study.

280 of 723 eligible patients did not want to participate. Data from June 2017 to July 2018. Reasons are listed according to frequency.

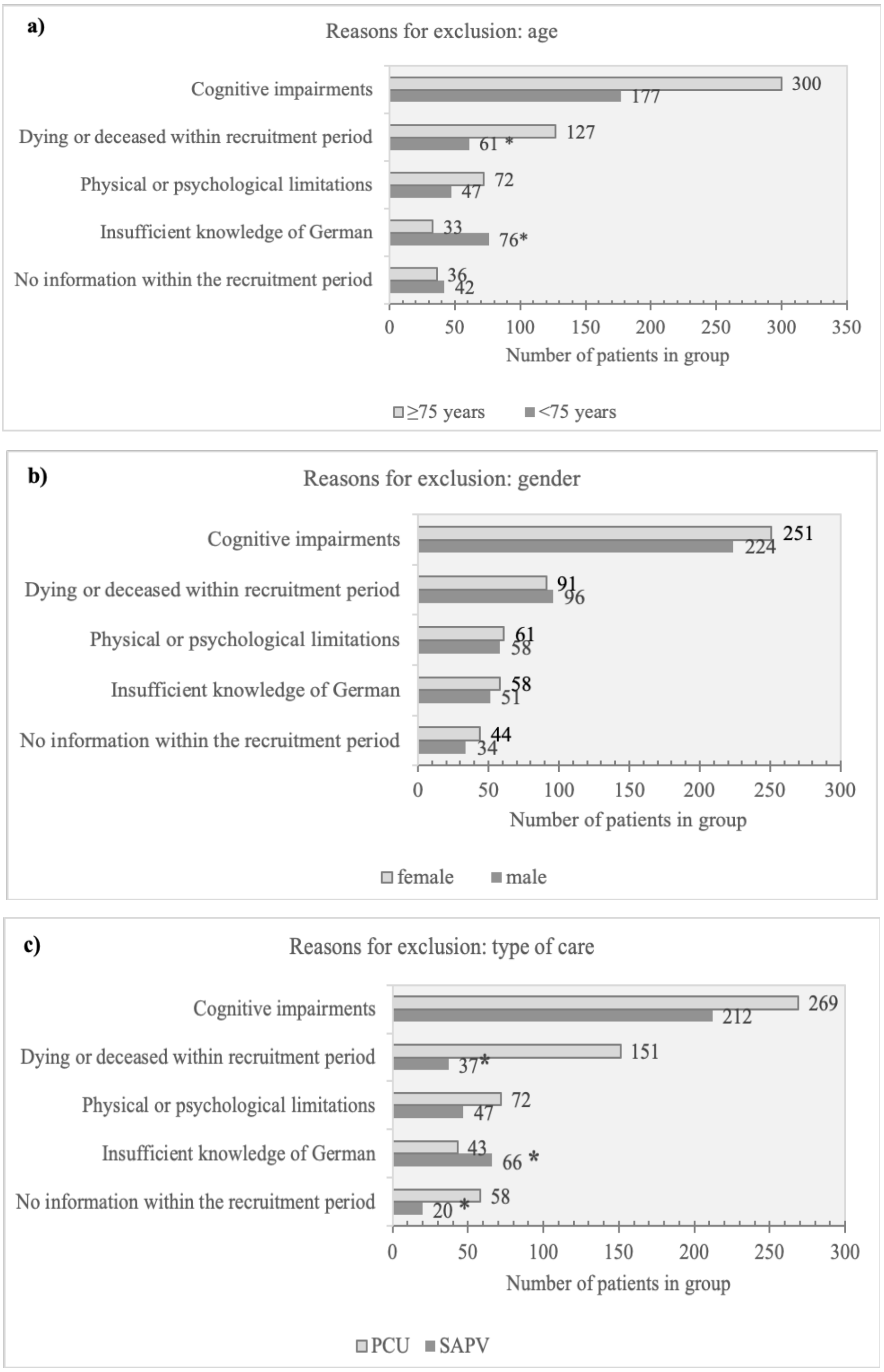

Figure 9: Group comparison of reasons for exclusion of the study in terms of a) age b) gender and c) type of care.

Reasons are listed according to frequency. Data available: a) age: N = 985 b) gender: N = 983 c) type of care: N = 990. * p < .017, adjusted p-value after Bonferroni correction due to multiple testing. Abbreviations: N = data available. PCU = palliative care unit, p = probability of type I error (binominal test to distribution in overall study population), SAPV = specialist outpatient palliative care.

4 Discussion

4.1 General Remarks

This study aimed to explore the presence and extent of physical, psychological, spiritual, and social problems, distress, unmet needs, depression, and anxiety as well as personal last wishes of patients newly admitted to specialist palliative care in Hamburg. Secondary questions concerned possible group differences in regard to age, gender and especially type of care (inpatient or outpatient specialist palliative care) and the influence of common problems to distress, depression, and anxiety.

The following results were seen clearly in the present analysis: Severely and terminally ill patients are very often seriously distressed at initiation of specialist palliative care. They experience a variety of problems, not only physically, but also psychosocially and are heavily affected in their every-day life. They have several unmet needs when entering SPC. Almost half of the patients suffer probably from depressive or anxiety disorders. More than half of severely and terminally ill patients expressed a last wish, most frequently related to travel. Group differences in regard to age, gender, and especially type of care could be detected only in individual problem frequencies.

The study population can be characterized as follows: The patients were 70 years old on average. The age is comparable to data collected from patients in SPC in Germany (2030 patients; mean age: 67 yrs. resp. 842 patients; mean age: 70 yrs.) (Jansky et al., 2012b; Lindena, 2017) and also to data from an international review about symptom prevalence in incurable cancer (25,074 patients; mean age: 64 yrs.) (Teunissen et al., 2007b). A vast majority of the respondents suffered from oncologic diseases. These characteristics are in line with previous analyses from patients in SPC in Germany (Jansky et al., 2012b) and in other European PCUs (Radbruch and Payne, 2009). Therefore, the findings of the present study are representative for the German population in specialist palliative care. As the patients participating in the study were at initiation of SPC, their perceptions were possibly influenced by fear and avoidance as patients with advanced cancer often associate palliative care with imminent death and end-of-life care at first (Zimmermann et al., 2016).

4.2 Evaluation of Psychosocial Distress and Potential Reasons at Initiation of Specialist Palliative Care

In the present study almost all the patients were distressed, half of them even severely. Psychosocial distress did not differ between the groups in regard to age, gender, and type of care despite differences in the frequency and type of individual problems. A study in Germany found high levels of psychosocial distress in 52% of cancer patients (n = 3,724) and an average of eight problems (Mehnert et al., 2018). The results of the present study show clearly that severely or terminally ill patients at initiation of SPC are even more distressed compared to the cancer patients in earlier stages of the study of Mehnert et al. and have more problems, especially on a physical and emotional level (Mehnert et al., 2018).

Patients in the present study named on average 15 problems, indicated in the DT problem list. The three most common problems were fatigue (92%), exercise/mobility (91%), and pain (76%). Half of the patients reported at least ten physical problems, three - quarters at least two emotional problems such as worries (64%), fears (62%), and sadness (62%).

Patients at initiation of SPC in Hamburg suffered from similar symptoms as severely and terminally ill patients worldwide. An international review from Teunissen et al. (2007) about symptom prevalence in incurable cancer differentiated between two groups, (1) overall symptom prevalence (including 25,074 patients) and (2) symptom prevalence during the last one to two weeks of life (including 2,219 patients). Fatigue (74%), pain (71%), lack of energy (69%), weakness (60%), and appetite loss (53%) occurred in more than 50% of the patients. During the last one to two weeks of life fatigue (88%), weight loss (86%), weakness (74%), and appetite loss (56%) were the most common symptoms (Teunissen et al., 2007). Several German studies have found a similar symptom burden as well (Escobar Pinzón et al., 2012; Götze et al., 2014; Jansky et al., 2012). Studies based on questionnaires compared to studies relying on standardized interviews found a higher prevalence of symptoms (Teunissen et al., 2007). The present study was also based on a questionnaire. This indicates that most of the symptoms of patients at initiation of SPC were recorded in the present study, so the obtained data are reliable for the condition of patients newly admitted to SPC in Germany.

In the results of the present study, fatigue was even more prevalent, mentioned by almost all patients. This shows that an appropriate approach in dealing with fatigue is a crucial element in palliative care. While treating fatigue in the early stages of the disease remains important, fatigue may protect patients in the final phase from suffering and a treatment may therefore not be indicated anymore. Fatigue can easily be assessed. According to German Standards of Procedures (SOP) for SPC, just a single item is suitable for screening: "I feel unusually weak / tired" (Cuhls et al., 2017).

Pain was reported from three - quarters of the patients at initiation of SPC. Pain is a major health care problem for patients with cancer and is shown to be undertreated in almost one of two patients despite the existence of guidelines for cancer pain management (Deandrea et al., 2008). In a recent Canadian study examining 20,349 deceased persons, severe pain was reported in less than one in five patients in the last month of life. One fifth of decedents (22%) receiving palliative home care confirmed severe pain and terminally ill patients (i.e. cancer) had higher odds of reporting pain (Hagarty et al., 2020).

The results of the present study indicate that symptom prevalence can be different in the frequency of single problems in regard to age, gender, and type of care. Age and gender differences are rarely looked at and if so, there seem to be limited relations (Teunissen et al., 2007). In one of the few studies examining differences in symptoms of patients with advanced cancer, these were corrected for diagnosis (Walsh et al., 2000). The results of the present study are similar to the analysis of Walsh et al. (2000): unlike gender, the effect of age seems to be unidirectional. Younger patients more often confirmed worries and sadness. Perhaps they are under a different kind of distress than older patients. In the present study, sexual problems were more frequent in younger patients and in men. While most of these results could be expected, further research is needed to be able to better individualize treatment for differences in age and gender in the future. In the present study, certain physical symptoms were more increased in inpatients than outpatients such as fever, dry nose, tingling, and feeling swollen. It had been especially expected that inpatients in the present study would suffer from a higher symptom burden and more pain and dyspnea than outpatients comparable to the results of other German studies (Escobar Pinzón et al., 2012; Jansky et al., 2012). But overall, it was striking that the average number of symptoms was not different between inpatients and outpatients in the present study. Regarding only individual symptoms, one should keep in mind, that significant statistical differences may not play an important role in the actual treatment (Walsh et al., 2000).

4.3 Evaluation of Problems and Needs at Initiation of Specialist Palliative Care

The present study showed that severely and terminally ill patients experience a wide variety of problems and needs outside the physical area at initiation of SPC. Every item on our version of the PNPC-sv was experienced from almost one in five patients as a problem (physical symptoms were not asked for). The three most prevalent problems concerned daily activities: difficulties in continuing the usual activities (90%), personal transportation (88%) and doing light housework (84%). Of patients reporting problems, a remarkably high percentage, at least one of three patients for each specific problem, had unmet needs at the time of their admission to SPC. The most common unmet needs were insufficient information (83%), extra expenditures (62%), and loss of income (60%). The findings of the present study are mostly in line with the results of the implementation study of the PNPC Questionnaire in the Netherlands (Osse et al., 2005).

It is highly alerting that so many patients experience problems and needs if asked specifically at initiation of SPC. The DT including the problem list (Mehnert et al., 2006) is recommended in the German guidelines for an assessment of the needs of severely and terminally ill patients (Leitlinienprogramm Onkologie et al., 2020). Spiritual issues could be better assessed with the PNPC - Questionnaire: While less than a tenth of the patients confirmed spiritual problems in the DT-problem list, about half of them considered spiritual issues as a problem in the PNPC Questionnaire.

Interestingly, there are also problems in the present study, such as personal transportation, where almost half of the patients wanted more support for this topic and almost one third did refrain from care. The percentage of the patients, who did not want professional attention despite experiencing a specific problem, must be considered. The question "Why a patient does not want care?" needs further research because of its clinical consequences (cf. Osse et al., 2005). For it is also important to consider in clinical care that some problems may need more attention, but others do not. While patients do not demand professional support for every single one of their problems, differentiation between problems and needs seems advisable for assessments in routine care.

According to a review summarizing the self-reported unmet needs of patients in home-based specialist palliative care, unmet needs are especially reported in psychosocial domains, while physical needs seem to be adequately accounted for (Ventura et al., 2014). This indicates a structural deficit, where action is needed. The planned investigation of the Hamburg study into possible changes throughout the course of SPC may uncover if SPC can in fact meet the needs of severely and terminally ill patients.

The results of the present study show that the frequency of individual problems and needs can be different in regard to age, gender, and type of care. The effect of age was again unidirectional unlike gender. Younger patients had more emotional and financial problems in contrast to older patients. More outpatients than inpatients declared that insufficient information is a problem. Unmet needs concerning body care were also more frequent in outpatients. This indicates that possible care deficits of outpatients in contrast to inpatients must be considered as well.

4.4 Evaluation of Anxiety and Depression at Initiation of Specialist Palliative Care

Overall, almost half of the patients suffer probably from depressive or anxiety disorders, with half of the patients being suspect for depression and slightly less for anxiety.

This is much higher than in the general German population as a control, where only 5% (≥ 75 yrs.: 9%) reach the cut-off value for being suspect of depression or anxiety (Löwe et al., 2010). Accordingly, international studies show that 30 to 50% of patients with advanced cancer or during palliative care suffer from mental disorders (Götze et al., 2014; Miovic and Block, 2007; Mitchell et al., 2011). Though it is important to notice that anxiety disorders of patients in palliative care occur often, which can be referred to as subsyndromal disorders and specific fears (Leitlinienprogramm Onkologie et al., 2014; Mehnert, 2015). These specific fears can be divided in situational, e.g., fear of possible symptoms, physical, e.g., fear induced by metabolic disorders, and existential fears, e.g., fear of the finiteness of one's own life (Leitlinienprogramm Onkologie et al., 2020). There are multiple causes of specific fears (Howell et al., 2015). It remains to be investigated what kind of fears are dominant in patients of the present study.

There seem to be under- and overestimations of psychiatric disorders in palliative care patients (Mehnert, 2015; Pessin et al., 2005). Koch and Mehnert (2005) stated that palliative care is a neglected issue in psychosocial research in Germany. There are indications that mental disorders are often not recognized (50%) and not adequately treated (35%) (Bundespsychotherapeutenkammer, 2015; Durkin et al., 2003). There are also indications that health professionals in palliative care recognize depression but underestimate its severity (Meyer et al., 2003). This can be due to difficulties in identifying the psychological symptoms against the background of the dominant physical symptoms. Therefore, more research about psychological and social problems of palliative care patients is needed (Koch and Mehnert, 2005). The "task of encouraging patients to actively deal with the treatment situation, to promote quality of life and at the same time to enable the acceptance of "realistic" therapy goals and treatment decisions, which in turn affect the psychosocial well-being of the patient and his relatives in the further course of the disease" is challenging for psychologists or psychotherapists (Mehnert, 2015; Mehnert and Schulz-Kindermann, 2016).

In the present study there could not be detected any differences in rates for depression and anxiety in regard to age, gender, or type of care. More women than men reported emotional symptoms in the DT-problem list. Looking at the PHQ-4 results the differences in regard to emotional symptoms between men and women, and age groups could not be found. This indicates that the PHQ-4 test may help uncover feelings of anxiety and depression and can therefore be used for screening in SPC.

With a report from the University Medical Center Hamburg-Eppendorf (part of the National Cancer Plan from 2016 to 2018), there is a comprehensive survey of psycho-oncological and psychosocial offers in Germany available. Especially outpatient psycho-oncological-psychotherapeutic care is currently considered insufficient. Patients in PCUs generally have better access to specialist psychological care. In addition to doctors and nursing staff, a psychologist / psychotherapist / psycho-oncologist can be a third team member for inpatient SPC. In contrast, maintaining psycho-oncological expertise in SAPV-teams is more difficult. Therefore, it seems necessary to specify the professional groups in the psychosocial field and to adapt the structure for SAPV teams (Alt-Epping and Nauck, 2015; Hornemann et al., 2019).

This is also important because lower levels of social support and self-esteem were strongly associated with higher levels of depressive symptoms in newly diagnosed cancer patients and could predict future levels of depression (Schroevers et al., 2003).

4.5 Influencing Factors for Higher Psychosocial Distress, Depression, and Anxiety at Initiation of Specialist Palliative Care

Multivariate testing of potential influencing problems revealed the following predictors for higher distress: difficulties with body care, washing, dressing, or toilet and experiencing loss of control over one’s life. For being suspect of depression: difficulties in continuing the usual activities, the difficulty in coping with the unpredictability of the future, difficulties to be of avail for others, and difficulties to give tasks out of hands. And for being suspect of anxiety: difficulties with doing light housework, the difficulty in coping with the unpredictability of the future, experiencing loss of control over one’s life, difficulties to be of avail for others, difficulties to accept the disease, and difficulties to give tasks out of hands.

In a previous study, sleep problems, fatigue, and sadness indicated higher distress and are potentially acting as predictors for the development of mental disorders (Mehnert et al., 2018). The problems detected in the present study could also help medical personnel if no routine screening for distress and mental disorders is available to evaluate the patient’s condition. In addition, these problems indicate which health structures must be changed to meet the needs of severely and terminally ill patients and to prevent mental disorders.

Therefore, it would be very interesting to further investigate influencing factors on higher distress, depression, and anxiety in palliative care patients in the future.

4.6 Personal Last Wishes of Severely and Terminally Ill Patients

More than half of the patients expressed at least one last wish at initiation of SPC. Qualitative analysis revealed eight categories: travel, activities, health, quality of life, family and friends, dying "well", turn back time, and getting affairs organized. Travel was mentioned most often. Overall, three - quarters of the inpatients confirmed a wish in contrast to just two - thirds of the outpatients.

Similar end-of-life wishes are mentioned in previous studies about patients with advanced cancer (Delgado-Guay et al., 2016; Masterson et al., 2018), as well as in the general population (Periyakoil et al., 2018; Rawlings et al., 2018). To address this need teams of medical volunteers traveling to severely and terminally ill patients with an ambulance to help fulfill their wishes already exist. First founded in the Netherlands there are now several such services worldwide.[6]

Some researchers have examined existential distress among patients with advanced disease, but the concept of unfinished business is not yet explored in detail. In a study of 2018 unfinished business was both prevalent and distressing in a sample of patients with advanced cancer (Masterson et al., 2018). It was also shown that an early end-of-life discussion can lead to less aggressive care and greater use of hospice (Mack et al., 2012). A basic requirement for the death in the desired place is the communication of this wish to the treating doctors, nurses, and relatives. Advance directives could be used as a support for communication and a cooperation between doctors and patients based on shared-decision making (van Oorschot et al., 2004). 'Advance care planning' is an important aspect of palliative care, having come into focus in the last years. It could be an idea to have a bucket list to engage patients in making decisions about their healthcare and to help medical professionals to relate treatment options to their potential impact within the framework of informed decision making. Because "true personalized care requires that clinicians have a clear understanding of what matters most to patients and what they wish to accomplish in their lives both short term and long term" (Periyakoil et al., 2018). The high number of wishes expressed by the patients shows that further research is needed to explore these desires in detail.

---

[6] https://www.ambulancewens.nl/en/aboutus, accessed 25.08.2021.

4.7 Recruitment of Severely and Terminally Ill Patients to a Longitudinal Study

In the context of a large longitudinal multicenter exploratory study, the aim of the present study was also to identify reasons for ineligibility and non-participation of severely and terminally ill patients who were newly admitted to specialist palliative care in Hamburg. Overall, 1,713 patients were newly admitted to specialist palliative care during the investigation period. One of the primary challenges during recruitment was the high drop-out rate of almost two- thirds of the patients which was substantially higher than the one quarter originally estimated during the trial design. Many patients were not able anymore to fill out a questionnaire mostly because of cognitive limitations (50%) or imminent death (19%). Furthermore, almost one fifth of the patients did not want to participate at all. Reasons mentioned for non-participation indicated a high distress in these patients.

These results, though, are in line with other studies. For example, Stone et al. (2013) examined recruitment to a large multicenter observational study recording the reasons for failure to recruit at “three key potential bottlenecks”: eligibility, accessibility, and consent. Exclusion criteria differed from our study though and did not include cognitive impairments. Reasons for non-participation were not recorded. The most common reason for patients not being assessed was that they died before review (24%, n = 1,126). This was more prevalent in community patients, while in the present study this was more common for inpatients. Gatekeeping, that is intermediaries trying to protect vulnerable patients, came second (24%, n = 1,101) in the Stone study. It could not be shown to what extent gatekeeping was indeed justified and to what extent it was due to clinical staff paternalistically “protecting” their patients from the additional burden of research (Stone et al., 2013). There have also been reports of medical personnel considering it “unethical” to include “patients who may be vulnerable in demanding research studies” (Casarett and Karlawish, 2000). In the present study there are some indications that gatekeeping played a role as well, although to a lower extent, as patients were excluded because of “too high psychological stress” (n = 30) and also because of “reduced general condition, weakness, high symptom burden” (n = 66). A possible strategy to avoid gatekeeping could be for example a study design that is “relevant, quick and easy to do, and not too demanding” (Jordhøy et al., 1999).

Ling et al. examined 1,206 patients who were applicable to participate in one of 23 clinical trials in palliative care. In this study 558 patients (46%) fulfilled the entry criteria, of whom 362 (30%) agreed to participate. The authors summarized their results as follows: “The most common reasons given for unwillingness to participate were a wish to defer to a later date, a deterioration in condition, distance from home to hospital, a lack of interest, transfer to another unit, inability to give consent, and family objection" (Ling et al., 2000). In a study concerning patients with advanced cancer in Denmark and their possible participation in a family coping intervention, the most common reasons for non-participation (n = 148) were "too soon" (32%, n = 65,) and "illness burden too great" (23%, n = 42) (Ammari et al., 2015). In a study about the willingness of patients in SPC to participate in studies in the UK only 50% of the patients (n = 100) had been considered "physically and mentally fit" for an interview. The most common reasons for exclusion had been "cognitive impairment" (n = 42) and "physical frailty" (n = 39). Finally, 24 patients (of 40 participants, mean: 69 years, all advanced malignancy) had said, that they would take part in a "study involving mood assessment and an interview" (Ross and Cornbleet, 2003). Keeping in mind the hypothetical character of that question and the small study-design, the results are nonetheless comparable to findings in the present study, where 61% of the eligible patients participated. The most common themes in a review studying attitudes of patients with advanced cancer towards research were altruism and possible self-benefit as well as maintaining hope (Todd et al., 2009). Overall though, in other studies there was no evidence of a general objection or refusal of palliative care patients to participate in research or clinical trials. If a study promised a relieve in symptoms or an amelioration of the care of future patients, palliative care patients generally agreed to hypothetically participate in studies. Accordingly, patients should not be excluded from research only because their symptoms have already progressed to a critical status (Pautex et al., 2005).

In addition, the high number of excluded and critically ill patients (50% cognitive impairments, 19% close to imminent death) newly admitted to SPC in Hamburg could indicate a continued late referral to SPC despite the efforts to integrate palliative care early in the disease trajectory. For example, studies from patients with advanced cancer show that "palliative care referral occurs late in the disease process with many missed opportunities for referral" despite the presence of an active interdisciplinary PC-team (Hui et al., 2012) and "in the context of uncontrolled symptoms" (Wentlandt et al., 2012).

There is now extensive evidence for the need of an early integration of palliative care in systematic reviews (Gaertner et al., 2017; Haun et al., 2017; Kavalieratos et al., 2016). First studies had shown that the early inclusion of specialist palliative care leads to an improvement in the quality of life of the patients, less depressive symptoms, less chemotherapy in the last few days of life, and a better prognostic understanding of the disease

(Bakitas et al., 2009; Bauman and Temel, 2014; Temel et al., 2010; Zimmermann et al., 2014). Temel et al. (2010) even demonstrated a prolonged survival of patients with non-small cell lung cancer when early assigned to palliative care. In a study of data from a German health insurance fund, patients treated with palliative care did not show any worse and in some cases even better survival probabilities than patients of the respective control groups (Plaul and Karmann, 2017). In the previously mentioned reviews, it is shown that there are various components of early integration of PC. There is one study that links the content of PC visits to outcome and demonstrates that a focus on coping, treatment decisions, and advance care planning is associated with improved patient outcomes (Hoerger et al., 2018). The creation of the necessary structural conditions for an early integration of palliative care treatment is an important task for the future (Gärtner et al., 2016), in particular also because clinicians tend to overestimate survival time of terminally ill patients (Glare, 2003). Vanbutsele et al. also show that a structured integration of SPC is better than an integration triggered by clinicians (Vanbutsele, 2020).

4.8 Strengths and Limitations of the Present Study

A strength of the study is the longitudinal multicenter explorative design with a high number of patients, who represent the conditions in the actual SPC in Germany. By systematically collecting information of all the patients, who were newly admitted to SPC in Hamburg for 12 months, it was possible to quantify the recruitment to a study in SPC and examine who is not able or willing to participate in longitudinal observant studies. Furthermore, the result is a detailed data base about problems, needs, distress, anxiety, and depression of severely and terminally ill patients at initiation of SPC in Hamburg. This enables further surveys about changes during the course of SPC.

Nevertheless, there are several methodological limitations of this study, which must be kept in mind while drawing conclusion from the data. Generalizability of the results may be limited because many patients at initiation of SPC were not able anymore to fill out a questionnaire, mostly because of cognitive limitations (50%) or because of imminent death (19%). Some patients (12%) were excluded because of a high psychological distress (n = 30) and also because of a reduced general condition (n = 89). This can be seen as hints for gatekeeping (as already discussed in 4.7). Furthermore 11% of the patients had to be excluded because their knowledge of the German language was not sufficient for completing the questionnaire. This could be problematic because SPC should address the problems and needs of all patients regardless of their origin. In addition, some patients (34% of non-participants) declined the participation because of being too distressed. This could suggest that patients at initiation of SPC are even more burdened than stated in the data of the present study and may have resulted in the prevalence of symptoms, problems and needs being underestimated. More outpatients than inpatients responded to the questionnaire. In contrast, more inpatients than outpatients were excluded from the study. This could indicate that the general condition of inpatients is in fact worse, similar to results from other studies. A vast majority of the patients (90%) who had filled out the questionnaire, had oncologic diseases. Therefore, patients with non-malignant diseases are most probably underrepresented in the present study. Demand estimates assume a significantly higher number of these patients in a palliative disease situation with a ratio of 60% tumors and 40% other diseases (Hess et al., 2014; Radbruch et al., 2011; Radbruch and Payne, 2009). Additionally, the mean age of the study population was high and therefore young patients with potentially different perceptions have to be kept in mind. Also, the study took place in an urban area, and it remains uncertain if the results could be transferred to more rural regions, where problems and unmet needs of severely and terminally ill patients could also be attributed to a lack of care infrastructure.

4.9 Clinical and Scientific Implications of the Present study

Based on our findings, the following implications regarding future practical palliative care should be strongly considered. First, palliative care should be thought of early in the disease trajectory, at best directly at diagnosis. In the beginning, low threshold offers such as flyers can be sufficient for the information of patients about palliative care. Later, there should be active offers to talk about the possible forms of support. It is desirable to include patients with non-oncologic diseases such as heart failure or chronic obstructive pulmonary disease as well.

Second, it is important to assess possible care deficits of severely and terminally ill patients. For this a differentiation of problems and needs can be helpful, meaning to evaluate for which problems the patients expect additional professional support. An individual bucket list of patients' whishes could be an incentive for a more personalized care. It is a good starting basis to discuss different treatment and support options with terminally and severely ill patients.

Third, an alignment of German health care structures should be pursued. In our study inpatients and outpatients seemed equally distressed and both groups were highly suspect for anxiety disorders and depression. Therefore, the development of concepts is necessary to ensure an equally sufficient psychologic support. The interdisciplinary approach of palliative care, which is already offered in palliative care units by multiprofessional teams, should be implemented also in home-based care. This means, that the SAPV-teams, which are mostly bi-professional up to now (physicians and nurses), should be multiprofessional by law.

A further scientific evaluation if and how problems and needs of severely and terminally ill patients change during SPC is already planned. It is necessary to investigate if the current support offers really meet the problems and needs of these patients. Additionally, it would be of great interest to further investigate factors which might have an impact on stress, depression, and anxiety of terminally ill patients. Here, the first step could be a retrospective control study including sociodemographic and care-related characteristics. Further research is also needed to explore personal last wishes of severely and terminally ill patients in detail. This can be realized by a prospective explorative study design.

4.10 Conclusion

Overall, the present study explored quantitatively and qualitatively the situation of severely and terminally ill patients at initiation of SPC. Many of the newly admitted patients were already at a late state of the disease. The respondents were severely distressed, suffered from a variety of problems and unmet needs and half of them were suspect for depression or anxiety disorders. There were almost no differences in the situation from outpatients and inpatients at initiation of SPC.

The results of the current study can be helpful to improve the quality of SPC even more in future. The referral to SPC still happened very late in the course of the disease. Especially the need for more information about the disease and treatment possibilities was unfulfilled for many patients at initiation of SPC. One possibility to reach an early integration of SPC into the treatment of severely and terminally ill patients, would be to inform the patients sooner about the option of SPC. Furthermore, it will be important to align the structure of the German health care system, so that outpatients have access to the same therapies as inpatients. For example, already existing inpatient therapies, such as psycho-oncology, physiotherapy, or music therapy, must be assured in home-based care. In doing so, the multiprofessional and interdisciplinary approach of palliative medicine can be implemented for outpatients as well as inpatients.

Abstract / Zusammenfassung

Abstract: The aim of the present study was to explore the presence and extent of problems, psychosocial distress, unmet needs, depression, and anxiety, as well as personal last wishes of patients at initiation of specialist palliative care (SPC). In the context of a large multicenter exploratory study reasons for ineligibility and non-participation were also identified. The analysis is based on data collected at three specialist palliative home care services and three palliative care units in Hamburg. Participants completed the Distress Thermometer, Problem and Needs in Palliative Care Questionnaire, Patient Health Questionnaire – Module 4 and an open question on personal last wishes. 1,713 patients were newly admitted to SPC. 990 patients had to be excluded (49% cognitive impairments, 19% imminent death). 425 patients were included into the analysis (92% cancer). Of these patients 50% were severely distressed at initiation of SPC, 40% were suspect of depressive or anxiety disorders. They experienced diverse problems and unmet needs. 57% of the patients expressed a last wish. The situation of outpatients and inpatients did not differ at initiation of SPC. Therefore, it will be important to align the structure of the German health care system in the future, so that outpatients have access to the same therapies as inpatients.

Zusammenfassung: Studienziel war es, das Vorhandensein und Ausmaß von Problemen, Belastung, unerfüllten Bedürfnissen, Depressionen und Angst sowie letzten Wünschen zu Beginn der spezialisierten Palliativversorgung (SPV) zu untersuchen. Im Rahmen einer multizentrischen explorativen Studie wurden auch Gründe für die Nichtteilnahme erhoben. Die Analyse basiert auf Daten von drei spezialisierten ambulanten Palliativteams sowie drei Palliativstationen in Hamburg. Die Teilnehmenden beantworteten einen Fragebogen bestehend aus Distress Thermometer, Problem and Needs in Palliative Care Questionnaire, Patient Health Questionnaire – Modul 4 und einer offenen Frage zu persönlichen letzten Wünschen. 1.713 Patient:innen wurden im Studienzeitraum neu in die SPV aufgenommen. 990 mussten ausgeschlossen werden (49% kognitive Beeinträchtigungen, 19% nahender Tod). 425 wurden in die Analyse eingeschlossen (davon 92% krebserkrankt). Die Hälfte war sehr stark belastet, bei 40% gab es Hinweise auf eine Depression oder Angsterkrankung. Die Patient:innen litten unter verschiedensten Problemen und unerfüllten Bedürfnissen. 57% äußerten einen persönlichen letzten Wunsch. Die Situation von ambulanten und stationären Patient:innen unterschied sich zu Beginn der SPV nicht. Daher ist es wichtig, die Struktur des deutschen Gesundheitswesens so anzupassen, dass Patient:innen im ambulanten und im stationären Bereich Zugang zu den gleichen Therapie - Möglichkeiten haben.

List of Abbreviations

General Abbreviations:

c.f.	compare *(confer)*
DT	Distress-Thermometer, see also NCCN-DT
DSM-IV	Diagnostic and Statistical Manual of Mental Disorders – Edition IV
EAPC	European Association for Palliative Care
e.g.	for example *(exempli gratia)*
GAD-2	General Anxiety Disorders - Scale 2
HOPE	Hospice and Palliative Care Evaluation
HPG	Hospice and Palliative Care Act (“Hospiz- und Palliativgesetz”)
i.e.	that is *(id est)*
yrs.	years
NCCN-DT	Distress Thermometer from the National Comprehensive Cancer Network
PCU	Palliative Care Unit
PNPC-sv	Problems and Needs in Palliative Care Questionnaire – Short Version
PHQ-2	Patient Health Questionnaire - Module 2
PHQ-4	Patient Health Questionnaire – Module 4
SAPV	Specialist Outpatient Palliative Care (In German: Spezialisierte Ambulante Palliativversorgung)
SPC	Specialist Palliative Care
WHO	World Health Organisation

Statistical Abbreviations:

ß	unstandardized regression coefficient
χ^2	Pearson's chi-squared test
CI	confidence interval
df	degrees of freedom
M	mean
Md	median
Ñ	number of patients included into analysis
N	statistical population/ number of patients who completed item
n	sample size/ number of patients who confirmed item

OR	odds ratio
p	probability of type I error
%	valid percent
phi	effect size (measure of association for two binary variables)
r	effect size is denoted by r
R	range
SD	standard deviation
SE	standard error
t	Student’s t-test
U	Mann–Whitney U test

List of Figures and Tables

List of Figures:

List of Tables:

Bibliography

Alt-Epping, B., Nauck, F., 2015. Spezialisierte Ambulante Palliativversorgung (SAPV): Vernetzung von Sektoren, Disziplinen und Professionen. Bundesgesundheitsbl. 58: 430–435. https://doi.org/10.1007/s00103-015-2125-6.

Ammari, A.B.H., Hendriksen, C., Rydahl-Hansen, S., 2015. Recruitment and Reasons for Non-Participation in a Family-Coping-Orientated Palliative Home Care Trial (FamCope). J Psychosoc Oncol. 33: 655–674. https://doi.org/10.1080/07347332.2015.1082168.

Bakitas, M., Lyons, K.D., Hegel, M.T., Balan, S., Brokaw, F.C., Seville, J., Hull, J.G., Li, Z., Tosteson, T.D., Byock, I.R., Ahles, T.A., 2009. Effects of a Palliative Care Intervention on Clinical Outcomes in Patients With Advanced Cancer: The Project ENABLE II Randomized Controlled Trial. JAMA. 302(7): 741-749. https://doi.org/10.1001/jama.2009.1198.

Basch, E., Deal, A.M., Dueck, A.C., Scher, H.I., Kris, M.G., Hudis, C., Schrag, D., 2017. Overall Survival Results of a Trial Assessing Patient-Reported Outcomes for Symptom Monitoring During Routine Cancer Treatment. JAMA. 318(2): 197-198. https://doi.org/10.1001/jama.2017.7156.

Basch, E., Deal, A.M., Kris, M.G., Scher, H.I., Hudis, C.A., Sabbatini, P., Rogak, L., Bennett, A.V., Dueck, A.C., Atkinson, T.M., Chou, J.F., Dulko, D., Sit, L., Barz, A., Novotny, P., Fruscione, M., Sloan, J.A., Schrag, D., 2016. Symptom Monitoring With Patient-Reported Outcomes During Routine Cancer Treatment: A Randomized Controlled Trial. J Clin Oncol. 34: 557–565. https://doi.org/10.1200/JCO.2015.63.0830.

Bauman, J.R., Temel, J.S., 2014. The Integration of Early Palliative Care With Oncology Care: The Time Has Come for a New Tradition. J Natl Compr Canc Netw 12(12): 1763–1771. https://doi.org/10.6004/jnccn.2014.0177.

Bausewein, C., Fegg, M., Roller, S., Voltz, R., 2018. Patientenbedürfnisse, in: Leitfaden Palliative Care (Sechste Ausgabe). Urban & Fischer, pp. 1–16. https://doi.org/10.1016/B978-3-437-23315-9.00001-9.

Becka D., Riese, A., Rychlik, R. P. T., Huenges, B. Rusche, H., 2014. Stand der hausärztlichen Palliativversorgung in Deutschland. Ein systematischer Litereraturreview. Dtsch Med Wochenschr. 139(44): 2254-2258. https://doi.org/10.1055/s-0034-1387257.

Bundesgesetzblatt Teil I Nr.11, 2007. Gesetz zur Stärkung des Wettbewerbs in der gesetzlichen Krankenversicherung (GKV-Wettbewerbsstärkungsgesetz -GKV-WSG) vom 26.03.2007 Bonn [online] URL: http://www.bgbl.de/xaver/bgbl/start.xav?startbk=Bundesanzeiger_BGBl&jumpTo=bgbl107s0378.pdf [accessed 25.8.21].

Bundespsychotherapeutenkammer, 2015. Entwurf eines Gesetzes zur Verbesserung der Hospiz- und Palliativversorgung in Deutschland (Hospiz- und Palliativgesetz – HPG). Gesetzentwurf der Bundesregierung (BT-Drucksache 18/5170) - Stellungnahme der Bundespsychotherapeutenkammer vom 17.09.2015. Berlin [online] URL: https://www.bundestag.de/resource/blob/388338/394e67915a2bbc6ee1bfa4a0315dda0a/bundespsycbundespsychotherape--bptk--data.pdf [accessed 25.8.21].

Casarett, D.J., Karlawish, J.H.T., 2000. Are Special Ethical Guidelines Needed For Palliative Care Research? J Pain Symptom Manage. 20 (2): 130–139. https://doi.org/10.1016/S0885-3924(00)00164-0.

Chaiviboontham, S., 2011. Recruitment and retention challenges in research of palliative care in patients with advanced cancer. Prog Palliat Care 19(4): 185–188. https://doi.org/10.1179/1743291X11Y.0000000009.

Clark, D., 2007. From margins to centre: a review of the history of palliative care in cancer. Lancet Oncol. 8(5): 430–438. https://doi.org/10.1016/S1470-2045(07)70138-9.

Connor, S.R., Bermedo, M.C.S. (Ed.), Worldwide Palliative Care Alliance, World Health Organization, 2014. Global Atlas of Palliative Care at the End of Life. [online] URL: https://www.who.int/nmh/Global_Atlas_of_Palliative_Care.pdf [accessed 25.8.21].

Cuhls, H., Mochamat, Mücke, M., Jaspers, B., Jentschke, E., Hense, J., Wolf, C., Ostgathe, C., Radbruch, L., 2017. SOP – Fatigue. Onkol. 23: 462–468. https://doi.org/10.1007/s00761-017-0229-3.

Deandrea, S., Montanari, M., Moja, L., Apolone, G., 2008. Prevalence of undertreatment in cancer pain. A review of published literature. Ann Oncol. 19(12): 1985–1991. https://doi.org/10.1093/annonc/mdn419.

Delgado-Guay, M.O., Rodriguez-Nunez, A., De la Cruz, V., Frisbee-Hume, S., Williams, J., Wu, J., Liu, D., Fisch, M.J., Bruera, E., 2016. Advanced cancer patients' reported wishes at the end of life: a randomized controlled trial. Support Care Cancer. 24(10): 4273–4281. https://doi.org/10.1007/s00520-016-3260-9.

Deutsche Gesellschaft für Palliativmedizin, 2016. Deutsche Gesellschaft zur Palliativmedizin: Definitionen zur Hospiz- und Palliativversorgung. [online] URL: https://www.dgpalliativmedizin.de/images/DGP_GLOSSAR.pdf [accessed 25.8.21].

Deutsche Gesellschaft für Palliativmedizin, 2015. Wegweiser Hospiz- und Palliativversorgung in Deutschland (2015). Übersicht zum aktuellen Stand der Hospiz- und Palliativversorgung in Deutschland. [online] URL: https://www.wegweiser-hospiz-palliativmedizin.de [accessed 25.8.21].

Deutsche Gesellschaft für Palliativmedizin, Deutsche Hospiz- und PalliativVerband, Bundesärztekammer, 2010. Die Charta, Leitsatz 1, Gesellschaftspolitische Herausforderungen – Ethik, Recht und öffentliche Kommunikation. Die Charta Zur Betreuung Schwerstkranker und Sterbender Menschen in Deutschland. [online] URL: https://www.charta-zur-betreuung-sterbender.de/die-charta_leitsaetze_1.html (accessed 25.8.21).

DIMDI, 2018. Spezialisierte stationäre palliativmedizinische Komplexbehandlung 8-98e. OPS Version 2018. [online] URL: https://www.dimdi.de/static/de/klassifikationen/ops/kode-suche/opshtml2018/block-8-97...8-98.htm#code8-98e (accessed 25.8.21).

Donovan, K.A., Grassi, L., McGinty, H.L., Jacobsen, P.B., 2014. Validation of the Distress Thermometer worldwide: state of the science. Psychooncology. 23(3): 241–250. https://doi.org/10.1002/pon.3430.

Durkin, I., Kearney, M., O'Siorain, L., 2003. Psychiatric disorder in a palliative care unit. Palliat Med. 17(2): 212–218. https://doi.org/10.1191/0269216303pm670oa.

Escobar Pinzón, L.C., Claus, M., Zepf, K.I., Fischbeck, S., Weber, M., 2012. Symptom Prevalence in the Last days of Life in Germany: The Role of Place of Death. Am J Hosp Palliat Care. 29(6): 431–437. https://doi.org/10.1177/1049909111425228.

Escobar Pinzon, L.C., Claus, M., Zepf, K.I., Letzel, S., Fischbeck, S., Weber, M., 2011. Preference for Place of Death in Germany. J. Palliat Med. 14(10): 1097–1103. https://doi.org/10.1089/jpm.2011.0136.

Escobar Pinzón, L.C., Münster, E., Fischbeck, S., Unrath, M., Claus, M., Martini, T., Weber, M., 2010. End-of-life care in Germany: Study design, methods and first results of the EPACS study (Establishment of Hospice and Palliative Care Services in Germany). BMC Palliat Care. 9:16. https://doi.org/10.1186/1472-684X-9-16.

Gaertner, J., Siemens, W., Meerpohl, J.J., Antes, G., Meffert, C., Xander, C., Stock, S., Mueller, D., Schwarzer, G., Becker, G., 2017. Effect of specialist palliative care services on quality of life in adults with advanced incurable illness in hospital, hospice, or community settings: systematic review and meta-analysis. BMJ. 357: j2925. https://doi.org/10.1136/bmj.j2925.

Ganzeboom, H.B.G., 2010. A new international socio-economic index (ISEI) of occupational status for the international standard classification of occupation 2008 (ISCO-08) constructed with data from the ISSP 2002-2007; With an analysis of quality of occupational measurement in ISSP. Presented at the Annual Conference of International Social Survey Programme, Lisbon.

Ganzeboom, H.B.G., De Graaf, P.M., Treiman, D.J., 1992. A standard international socio-economic index of occupational status. Soc Sci Res. 21: 1–56. https://doi.org/10.1016/0049-089X(92)90017-B.

Ganzeboom, H.B.G., Treiman, D.J., 2003. Three internationally standardised measures for comparative research on occupational status, in: Hoffmeyer-Zlotnik, J.H.P., Wolf, C. (Eds.), Advances in Cross-National Comparison. A European Working Book for Demographic and Socio-Economic Variables. Kluwer Academic/ Plenum Publishers, New York, pp. 159–193.

Ganzeboom, H.B.G., Treiman, D.J., 2019. International Stratification and Mobility File: Conversion Tools. [online] URL: http://www.harryganzeboom.nl/ismf/ (accessed 25.8.21).

Gärtner, J., Jaroslawski, K., Thuss-Patience, P., Rosenbruch, J., Berendt, J., Becker, G., 2017. SOP – Aufnahmekriterien auf die Palliativstation. Onkol. 23: 300–302. https://doi.org/10.1007/s00761-017-0196-8.

Gärtner, J., Wedding, U., Alt-Epping, B., 2016. Frühzeitige spezialisierte palliativmedizinische Mitbehandlung. Z Palliativmed. 17(02): 83–93. https://doi.org/10.1055/s-0042-103068.

Geist, Markus J. P., Keßler, J., Bardenheuer, H., 2018a. Analyse der medizinischen Versorgung onkologischer und nichtonkologischer Palliativpatienten in der spezialisierten ambulanten Palliativversorgung (SAPV). Z Palliativmed 19(03): 149–155. https://doi.org/10.1055/s-0043-124478.

Geist, Marcus J. P., Keßler, J., Bardenheuer, H.J., 2018b. Stationäre Palliativmedizin – Analyse der medizinischen Versorgung onkologischer und nichtonkologischer Patienten einer universitären Palliativstation. Z Palliativmed 19(01): 39–46. https://doi.org/10.1055/s-0043-120048.

Gemeinsamer Bundesausschuss, 2018. Bericht an das Bundesministerium für Gesundheit über die Umsetzung der SAPV- Richtlinie für das Jahr 2016. [online] URL: https://www.g-ba.de/downloads/17-98-4474/Bericht-Evaluation-SAPV-2016.pdf (accessed 25.8.21).

Gemeinsamer Bundesausschuss, 2021. Richtlinie des Gemeinsamen Bundesausschusses zur Verordnung von spezialisierter ambulanter Palliativversorgung (Spezialisierte Ambulante Palliativversorgungs-Richtlinie / SAPV-RL). [online] https://www.g-ba.de/downloads/62-492-2468/SAPV-RL_2021-03-18_iK-2021-04-01.pdf (accessed 25.8.21).

Glare, P., 2003. A systematic review of physicians' survival predictions in terminally ill cancer patients. BMJ 327(7408): 195–198. https://doi.org/10.1136/bmj.327.7408.195.

Gnass, I., Krutter, S., Elsner, F., Osterbrink, J., 2016. Methodische Herausforderungen bei der Rekrutierung vulnerabler Patienten. Z Palliativmed 17(01): 38–43. https://doi.org/10.1055/s-0041-109800.

Gomes, B., Calanzani, N., Curiale, V., McCrone, P., Higginson, I.J., 2013. Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers. Cochrane Database Syst Rev. (6): CD007760. https://doi.org/10.1002/14651858.CD007760.pub2.

Götze, H., Brähler, E., Gansera, L., Polze, N., Köhler, N., 2014. Psychological distress and quality of life of palliative cancer patients and their caring relatives during home care. Support Care Cancer. 22(10): 2775–2782. https://doi.org/10.1007/s00520-014-2257-5.

Grande, G.E., Todd, C.J., 2000. Why are trials in palliative care so difficult? Palliat Med. 14(1): 69-74. https://doi.org/10.1191/026921600677940614.

Greer, D.S., Mor, V., Morris, J.N., Sherwood, S., Kidder, D., Birnbaum, H., 1986. An alternative in terminal care: Results of the national hospice study. J Chronic Dis. 39(1): 9–26. https://doi.org/10.1016/0021-9681(86)90103-7.

Groh, G., Vyhnalek, B., Feddersen, B., Führer, M., Borasio, G.D., 2013. Effectiveness of a Specialized Outpatient Palliative Care Service as Experienced by Patients and Caregivers. J Palliat Med. 16(8), 848–856. https://doi.org/10.1089/jpm.2012.0491.

Grov, E.K., Dahl, A.A., Moum, T., Fosså, S.D., 2005. Anxiety, depression, and quality of life in caregivers of patients with cancer in late palliative phase. Ann Oncol. 16(7): 1185–1191. https://doi.org/10.1093/annonc/mdi210.

Hagarty, A.M., Bush, S.H., Talarico, R., Lapenskie, J., Tanuseputro, P., 2020. Severe pain at the end of life: a population-level observational study. BMC Palliat. Care. 19(1): 60. https://doi.org/10.1186/s12904-020-00569-2.

Harms, D., Deckert, P.M., 2020. Spezialisierte ambulante Palliativversorgung (SAPV) und Allgemeinmedizin: Das Spezielle der SAPV aufgrund einer Literaturstudie und einer Befragung von Allgemeinmedizinern. Z Palliativmed 21(03): 121–127. https://doi.org/10.1055/a-1078-9804.

Haun, M.W., Estel, S., Rücker, G., Friederich, H.-C., Villalobos, M., Thomas, M., Hartmann, M., 2017. Early palliative care for adults with advanced cancer. Cochrane Database Syst Rev. 6(6): CD011129. https://doi.org/10.1002/14651858.CD011129.pub2.

Heckel, M., Stiel, S., Frauendorf, T., Hanke, R., Ostgathe, C., 2015. Retrospektive Datenanalyse von Patienten in der Spezialisierten Ambulanten Palliativversorgung (SAPV) – Vergleich zwischen Stadt und Landkreis. Gesundheitswesen. 78(07): 431–437. https://doi.org/10.1055/s-0034-1396807.

Hess, S., Stiel, S., Hofmann, S., Klein, C., Lindena, G., Ostgathe, C., 2014. 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. 25(2): 187–192. https://doi.org/10.1016/j.ejim.2013.11.012.

Higginson, I.J., Evans, C.J., 2010. What Is the Evidence That Palliative Care Teams Improve Outcomes for Cancer Patients and Their Families? Cancer J. 16(5): 423–435. https://doi.org/10.1097/PPO.0b013e3181f684e5.

Hoerger, M., Greer, J.A., Jackson, V.A., Park, E.R., Pirl, W.F., El-Jawahri, A., Gallagher, E.R., Hagan, T., Jacobsen, J., Perry, L.M., Temel, J.S., 2018. Defining the Elements of Early Palliative Care That Are

Associated With Patient-Reported Outcomes and the Delivery of End-of-Life Care. J Clin Oncol. 36(11): 1096–1102. https://doi.org/10.1200/JCO.2017.75.6676.

Hoffmeyer-Zlotnik, J.H.P., 2003. “Stellung im Beruf” als Ersatz für eine Berufsklassifikation zur Ermittlung von sozialem Prestige. ZUMA-Nachrichten 53: 114-127. [online] URL: https://nbn-resolving.org/urn:nbn:de:0168-ssoar-207760 [accessed 25.8.21].

Hoffmeyer-Zlotnik, J.H.P., Warner, U., 2011. Measuring occupation and labour status in cross-national comparative surveys, GESIS-Schriftenreihe. GESIS, Bonn. [online] URL: https://www.gesis.org/fileadmin/upload/forschung/publikationen/gesis_reihen/gesis_forschungsberifors/GS_7_-_Hoffmeyer-Zlotnik.pdf [accessed 25.8.21].

Hornemann, B., Schuler, U., Schütte, K., Hentschel, L., 2019. Psychoonkologisches Screening in der Palliativmedizin. Z Palliativmed 20(04): 193-204. https://doi.org/10.1055/a-0762-0668.

Howell, D., Keshavarz H., Esplen M.J., Hack T., Hamel M., Howes J., Jones J., Li M., Manii D., McLeod D., Meyer C., Sellick S., Riahizadeh S., Noroozi H., Ali M., on behalf of the Cancer Journey Advisory Group of the Canadian Partnership Against Cancer, 2015. A Pan-Canadian Practice Guideline: Screening, Assessment and Management of Psychosocial Distress, Major Depression and Anxiety in Adults with Cancer, Version 2. [online] URL: https://www.capo.ca/resources/Documents/Guidelines/3APAN-~1.PDF [accessed 25.8.21].

Hudson, P.L., Thomas, K., Trauer, T., Remedios, C., Clarke, D., 2011. Psychological and Social Profile of Family Caregivers on Commencement of Palliative Care. J Pain Symptom Manage. 41(3): 522–534. https://doi.org/10.1016/j.jpainsymman.2010.05.006.

Hui, D., Kim, S., Kwon, J.H., Tanco, K.C., Zhang, T., Kang, J.H., Rhondali, W., Chisholm, G., Bruera, E., 2012. Access to Palliative Care Among Patients Treated at a Comprehensive Cancer Center. Oncologist. 17(12): 1574–1580. https://doi.org/10.1634/theoncologist.2012-0192.

Hui, D., Mori, M., Watanabe, S.M., Caraceni, A., Strasser, F., Saarto, T., Cherny, N., Glare, P., Kaasa, S., Bruera, E., 2016. Referral criteria for outpatient specialty palliative cancer care: an international consensus. Lancet Oncol. 17(12): e552–e559. https://doi.org/10.1016/S1470-2045(16)30577-0.

Jansky, M., Lindena, G., Nauck, F., 2012. Befinden von Palliativpatienten im Verlauf einer spezialisierten ambulanten oder stationären Versorgung. Schmerz. 26: 46–53. https://doi.org/10.1007/s00482-011-1119-z.

Jansky, M., Lindena, G., Nauck, F., 2011. Stand der spezialisierten ambulanten Palliativversorgung (SAPV) in Deutschland – Verträge und Erfahrungen. Z Palliativmed 12(4): 166–174. https://doi.org/10.1055/s-0031-1276839.

Jordan, K., Aapro, M., Kaasa, S., Ripamonti, C.I., Scotté, F., Strasser, F., Young, A., Bruera, E., Herrstedt, J., Keefe, D., Laird, B., Walsh, D., Douillard, J.Y., Cervantes, A., 2018. European Society for Medical Oncology (ESMO) position paper on supportive and palliative care. Ann Oncol. 29(1): 36–43. https://doi.org/10.1093/annonc/mdx757.

Jordhøy, M.S., Kaasa, S., Fayers, P., Underland, G., Ahlner-Elmqvist, M., 1999. Challenges in palliative care research; recruitment, attrition and compliance: experience from a randomized controlled trial. Palliat Med. 13(4): 299–310. https://doi.org/10.1191/026921699668963873.

Kane, RobertL., Bernstein, L., Wales, J., Leibowitz, A., Kaplan, S., 1984. A randomised controlled trial of hospice care. Lancet. 1(8382): 890-894. https://doi.org/10.1016/S0140-6736(84)91349-7.

Kavalieratos, D., Corbelli, J., Zhang, D., Dionne-Odom, J.N., Ernecoff, N.C., Hanmer, J., Hoydich, Z.P., Ikejiani, D.Z., Klein-Fedyshin, M., Zimmermann, C., Morton, S.C., Arnold, R.M., Heller, L., Schenker, Y., 2016. Association Between Palliative Care and Patient and Caregiver Outcomes: A Systematic Review and Meta-analysis. JAMA. 316(20): 2104-2114. https://doi.org/10.1001/jama.2016.16840.

Koch, U., Mehnert, A., 2005. Palliative Care - A Neglected Issue in Psychosocial Research in Germany. Psychother Psychosom Med Psychol. 55(6): 281–282. https://doi.org/10.1055/s-2005-866901.

Kratel, U., 2014. Fortschritte in der ambulanten Palliative Care-Versorgung in Deutschland − Eine Bestandsaufnahme. Dtsch Z Onkol. 46(01): 8–15. https://doi.org/10.1055/s-0033-1357616.

Kroenke, K., Spitzer, R.L., Williams, J.B.W., 2003. The Patient Health Questionnaire-2: Validity of a Two-Item Depression Screener. Med Care 41(11): 1284–1292. https://doi.org/10.1097/01.MLR.0000093487.78664.3C.

Kroenke, K., Spitzer, R.L., Williams, J.B.W., Löwe, B., 2009. An Ultra-Brief Screening Scale for Anxiety and Depression: The PHQ–4. Psychosomatics. 50(6): 613–621. https://doi.org/10.1016/S0033-3182(09)70864-3.

Kroenke, K., Spitzer, R.L., Williams, J.B.W., Monahan, P.O., Löwe, B., 2007. Anxiety Disorders in Primary Care: Prevalence, Impairment, Comorbidity, and Detection. Ann Intern Med. 146(5): 317-325. https://doi.org/10.7326/0003-4819-146-5-200703060-00004.

Leitlinienprogramm Onkologie, Deutsche Krebsgesellschaft, Deutsche Krebshilfe, AWMF, 2020. S3-Leitlinie Palliativmedizin für Patienten mit einer nicht-heilbaren Krebserkrankung, Langversion 2.1, AWMF-Registernummer: 128/001OL. [online] URL: https://www.awmf.org/leitlinien/detail/ll/128-001OL.html [accessed 25.8.21].

Leitlinienprogramm Onkologie, Deutsche Krebsgesellschaft, Deutsche Krebshilfe, AWMF, 2014. S3-Leitlinie Psychoonkologische Diagnostik, Beratung und Behandlung von erwachsenen Krebspatienten, Langversion 1.1, AWMF-Registriernummer: 032/051OL. [online] URL: https://www.awmf.org/leitlinien/detail/ll/032-051OL.html [accessed 25.8.21].

Lindena, D.G., 2017. HOPE-Bericht 2017: Bericht Basisbogen. [online] URL: www.hope-clara.de [accessed 20.5.18]

Ling, J., Rees, E., Hardy, J., 2000. What influences participation in clinical trials in palliative care in a cancer centre? Eur J Cancer. 36(5): 621-626. https://doi.org/10.1016/s0959-8049(99)00330-5.

Löwe, B., Kroenke, K., Herzog, W., Gräfe, K., 2004. Measuring depression outcome with a brief self-report instrument: sensitivity to change of the Patient Health Questionnaire (PHQ-9). J Affect Disord. 81(1): 61–66. https://doi.org/10.1016/S0165-0327(03)00198-8.

Löwe, B., Wahl, I., Rose, M., Spitzer, C., Glaesmer, H., Wingenfeld, K., Schneider, A., Brähler, E., 2010. A 4-item measure of depression and anxiety: Validation and standardization of the Patient Health Questionnaire-4 (PHQ-4) in the general population. J Affect Disord. 122(1-2): 86–95. https://doi.org/10.1016/j.jad.2009.06.019.

Ma, X., Zhang, J., Zhong, W., Shu, C., Wang, F., Wen, J., Zhou, M., Sang, Y., Jiang, Y., Liu, L., 2014. The diagnostic role of a short screening tool—the distress thermometer: a meta-analysis. Support Care Cancer. 22(7): 1741–1755. https://doi.org/10.1007/s00520-014-2143-1.

Mack, J.W., Cronin, A., Keating, N.L., Taback, N., Huskamp, H.A., Malin, J.L., Earle, C.C., Weeks, J.C., 2012. Associations Between End-of-Life Discussion Characteristics and Care Received Near Death: A Prospective Cohort Study. J Clin Oncol. 30(35): 4387–4395. https://doi.org/10.1200/JCO.2012.43.6055.

Masterson, M.P., Slivjak, E., Jankauskaite, G., Breitbart, W., Pessin, H., Schofield, E., Holland, J., Lichtenthal, W.G., 2018. Beyond the bucket list: Unfinished and business among advanced cancer patients. Psychooncology. 27(11):2573-2580. https://doi.org/10.1002/pon.4821.

Mehnert, A., 2015. Psychotherapie in der palliativen Versorgung. Psychother Psychosom Med Psychol. 65(9-10): 387-396. https://doi.org/10.1055/s-0035-1552758.

Mehnert, A., Brähler, E., Faller, H., Härter, M., Keller, M., Schulz, H., Wegscheider, K., Weis, J., Boehncke, A., Hund, B., Reuter, K., Richard, M., Sehner, S., Sommerfeldt, S., Szalai, C., Wittchen, H.-U., Koch, U., 2014. Four-Week Prevalence of Mental Disorders in Patients With Cancer Across Major Tumor Entities. J Clin Oncol. 32(31): 3540–3546. https://doi.org/10.1200/JCO.2014.56.0086.

Mehnert, A., Hartung, T.J., Friedrich, M., Vehling, S., Brähler, E., Härter, M., Keller, M., Schulz, H., Wegscheider, K., Weis, J., Koch, U., Faller, H., 2018. One in two cancer patients is significantly distressed: Prevalence and indicators of distress. Psychooncology. 27(1): 75–82. https://doi.org/10.1002/pon.4464.

Mehnert, A., Müller, D., Lehmann, C., Koch, U., 2006. Die deutsche Version des NCCN Distress-Thermometers. Z Psychiatr Psychol Psychother. 54(3): 213–223. https://doi.org/10.1024/1661-4747.54.3.213.

Mehnert, A., Schulz-Kindermann, F., 2016. Psychoonkologische Unterstützung für Patienten mit begrenzter Lebenserwartung. Forum. 31: 135–139. https://doi.org/10.1007/s12312-016-0035-7.

Melching, H., 2019. Umsetzung des Hospiz- und Palliativgesetzes (HPG): Aktueller Stand. Forum. 34: 439–444. https://doi.org/10.1007/s12312-019-00672-3.

Mercadante, S., Intravaia, G., Villari, P., Ferrera, P., David, F., Casuccio, A., Mangione, S., 2008. Clinical and financial analysis of an acute palliative care unit in an oncological department. Palliat Med. 22(6): 760–767. https://doi.org/10.1177/0269216308094338.

Meyer, H.A.M., Sinnott, C., Seed, P.T., 2003. Depressive symptoms in advanced cancer. Part 2. Depression over time; the role of the palliative care professional. Palliat Med. 17(7): 604–607. https://doi.org/10.1191/0269216303pm813oa.

Miovic, M., Block, S., 2007. Psychiatric disorders in advanced cancer. Cancer 110(8): 1665–1676. https://doi.org/10.1002/cncr.22980.

Mitchell, A.J., Chan, M., Bhatti, H., Halton, M., Grassi, L., Johansen, C., Meader, N., 2011. Prevalence of depression, anxiety, and adjustment disorder in oncological, haematological, and palliative-care settings: a meta-analysis of 94 interview-based studies. Lancet Oncol. 12(2): 160–174. https://doi.org/10.1016/S1470-2045(11)70002-X.

Moghaddam, N., Coxon, H., Nabarro, S., Hardy, B., Cox, K., 2016. Unmet care needs in people living with advanced cancer: a systematic review. Support Care Cancer. 24(8): 3609–3622. https://doi.org/10.1007/s00520-016-3221-3.

National Comprehensive Cancer Network, 2020. NCCN Clinical Practice Guidelines in Oncology, Distress Management, Version 2.2020. NCCN.org.

Oechsle, K., Goerth, K., Bokemeyer, C., Mehnert, A., 2013. Symptom burden in palliative care patients: perspectives of patients, their family caregivers, and their attending physicians. Support Care Cancer. 21(7): 1955–1962. https://doi.org/10.1007/s00520-013-1747-1.

Osse, B.H.P., Vernooij, M.J.F.J., Schadé, E., Grol, R.P.T.M., 2004. Towards a new clinical tool for needs assessment in the palliative care of cancer patients: the PNPC instrument. J Pain Symptom Manage. 28(4): 329–341. https://doi.org/10.1016/j.jpainsymman.2004.01.010.

Osse, B.H.P., Vernooij-Dassen, M.J.F.J., Schadé, E., Grol, R.P.T.M., 2007. A practical instrument to explore patients' needs in palliative care: the Problems and Needs in Palliative Care questionnaire — short version. Palliat Med. 21(5): 391–399. https://doi.org/10.1177/0269216307078300.

Osse, B.H.P., Vernooij-Dassen, M.J.F.J., Schadé, E., Grol, R.P.T.M., 2005. The problems experienced by patients with cancer and their needs for palliative care. Support Care Cancer. 13(9): 722–732. https://doi.org/10.1007/s00520-004-0771-6.

Pautex, S., Herrmann, F.R., Zulian, G.B., 2005. Is Research Really Problematic in Palliative Care? A Pilot Study. J Pain Symptom Manage. 30(2): 109–111. https://doi.org/10.1016/j.jpainsymman.2005.05.010.

Periyakoil, V.S., Neri, E., Kraemer, H., 2018. Common Items on a Bucket List. J Palliat Med. 21(5): 652–658. https://doi.org/10.1089/jpm.2017.0512.

Pessin, H., Olden, M., Jacobson, C., Kosinski, A., 2005. Clinical assessment of depression in terminally ill cancer patients: A practical guide. Palliat Support Care. 3(4): 319–324. https://doi.org/10.1017/S1478951505050480.

Plaul, C., Karmann, A., 2017. Überlebensvorteil Palliativversorgung? – Eine empirische Analyse von Krebspatienten mittels Kaplan-Meier-Überlebensfunktionen. Z Palliativmed. 18(1): 44–50. https://doi.org/10.1055/s-0042-119219.

Prütz, F., Saß, A.-C., 2017. Daten zur Palliativversorgung in Deutschland. Bundesgesundheitsbl. 60: 26–36. https://doi.org/10.1007/s00103-016-2483-8.

Quill, T.E., Abernethy, A.P., 2013. Generalist plus Specialist Palliative Care — Creating a More Sustainable Model. N Engl J Med. 368(13): 1173–1175. https://doi.org/10.1056/NEJMp1215620.

Radbruch, L., 2019. Die Deutsche Gesellschaft für Palliativmedizin 2014 – 2019: Viel erreicht, aber noch lange nicht fertig! Z Palliativmed. 20(05): 216–219. https://doi.org/10.1055/a-0993-2450.

Radbruch, L., Bausewein, C., Simon, S., Sipp, W., Wodarg, W., Jünger, S., 2011. Europäische Empfehlungen zur Palliativversorgung und Hospizarbeit und ihre Umsetzung in Deutschland. Z Palliativmed. 12(04): 177–185. https://doi.org/10.1055/s-0030-1266142.

Radbruch, L., Payne, S., 2009. White Paper on standards and norms for hospice and palliative care in Europe: part 1. Recommendations from the European Association for Palliative Care. Eur J Pall Care 16, 278–

289. [online] URL: https://eapcresearchcongress2020.eu/wp-content/uploads/2020/11/White-Paper-on-standards-and-norms-for-hospice-and-palliative-care-in-Europe.pdf [accessed 25.8.21].

Radbruch, L., Payne, S., EAPC Board of Directors, 2010. White Paper on standards and norms for hospice and palliative care in Europe: part 2. Recommendations from the European Association for Palliative Care. Eur. J. Palliat. Care 17, 22–33. [online] URL: https://eapcresearchcongress2020.eu/wp-content/uploads/2020/11/White-Paper-on-standards-and-norms-for-hospice-and-palliative-care-in-Europe.pdf [accessed 25.8.21].

Ransom, S., Azzarello, L.M., McMillan, S.C., 2006. Methodological issues in the recruitment of cancer pain patients and their caregivers. Res Nurs Health. 29(3): 190–198. https://doi.org/10.1002/nur.20129.

Rawlings, D., Miller-Lewis, L., Tieman, J., 2018. Community Views on 'What I Want 'Before I Die.' Behav Sci (Basel). 8(12): 111. https://doi.org/10.3390/bs8120111.

Régincos, P., Nau, H., Hönemann, E.-M., 2020. Spannungsfeld stationäre-nachstationäre Versorgung in Palliative Care. Z Palliativmed. 21(01): 21–26. https://doi.org/10.1055/a-0993-1347.

Richter-Kuhlmann, E., 2017. Spezialisierte Ambulante Palliativversorgung: Es geht langsam voran. Dsch Arztebl. 114 (8).

Ross, C., Cornbleet, M., 2003. Attitudes of patients and staff to research in a specialist palliative care unit. Palliat Med. 17(6): 491–497. https://doi.org/10.1191/0269216303pm785oa.

Roth, A.J., Kornblith, A.B., Batel-Copel, L., Peabody, E., Scher, H.I., Holland, J.C., 1998. Rapid screening for psychologic distress in men with prostate carcinoma. Cancer. 82(10): 1904–1908. https://doi.org/10.1002/(SICI)1097-0142(19980515)82:10<1904::AID-CNCR13>3.0.CO;2-X.

Saunders, C., 2001. The Evolution of Palliative Care. J R Soc Med. 94(9): 430–432. https://doi.org/10.1177/014107680109400904.

Schmidt-Wolf, G., Elsner, F., Lindena, G., Hilgers, R.-D., Heussen, N., Rolke, R., Ostgathe, C., Radbruch, L., und die Förderprojekte der Deutschen Krebshilfe, 2013. Evaluation von 12 Pilotprojekten zur Verbesserung der ambulanten Palliativversorgung. Dtsch. Med Wochenschr. 138(50): 2585–2591. https://doi.org/10.1055/s-0033-1359858.

Schneider, N., Mitchell, G.K., Murray, S.A., 2010. Palliative care in urgent need of recognition and development in general practice: the example of Germany. BMC Fam Pract. 11:66. https://doi.org/10.1186/1471-2296-11-66.

Schroevers, M.J., Ranchor, A.V., Sanderman, R., 2003. The role of social support and self-esteem in the presence and course of depressive symptoms: a comparison of cancer patients and individuals from the general population. Soc Sci Med. 57(2): 375–385. https://doi.org/10.1016/S0277-9536(02)00366-0.

Scientific Advisory Committee of the Medical Outcomes Trust, 2002. Assessing health status and quality-of-life instruments: Attributes and review criteria. Qual Life Res. 11(3): 193–205. https://doi.org/10.1023/a:1015291021312.

Sepúlveda, C., Marlin, A., Yoshida, T., Ullrich, A., 2002. Palliative Care: The World Health Organization's Global Perspective. J Pain Symptom Manage. 24(2): 91–96. https://doi.org/10.1016/s0885-3924(02)00440-2.

Smith, T.J., Coyne, P., Cassel, B., Penberthy, L., Hopson, A., Hager, M.A., 2003. A High-Volume Specialist Palliative Care Unit and Team May Reduce In-Hospital End-of-Life Care Costs. J Palliat Med. 6(5): 699–705. https://doi.org/10.1089/109662103322515202.

Spitzer, R.L., Kroenke, K., Williams, J.B.W., Löwe, B., 2006. A Brief Measure for Assessing Generalized Anxiety Disorder: The GAD-7. Arch Intern Med. 166(10): 1092-1097. https://doi.org/10.1001/archinte.166.10.1092.

Steinhauser, K.E., Clipp, E.C., Hays, J.C., Olsen, M., Arnold, R., Christakis, N.A., Lindquist, J.H., Tulsky, J.A., 2006. Identifying, recruiting, and retaining seriously-ill patients and their caregivers in longitudinal research. Palliat Med. 20(8): 745–754. https://doi.org/10.1177/0269216306073112.

Stone, P.C., Gwilliam, B., Keeley, V., Todd, C., Kelly, L.C., Barclay, S., 2013. Factors affecting recruitment to an observational multicentre palliative care study. BMJ Support Palliat Care 3(3): 318–323. https://doi.org/10.1136/bmjspcare-2012-000396.

Temel, J.S., Greer, J.A., Muzikansky, A., Gallagher, E.R., Admane, S., Jackson, V.A., Dahlin, C.M., Blinderman, C.D., Jacobsen, J., Pirl, W.F., Billings, J.A., Lynch, T.J., 2010. Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer. N Engl J Med. 363(8): 733–742. https://doi.org/10.1056/NEJMoa1000678.

Teunissen, S.C.C.M., Wesker, W., Kruitwagen, C., de Haes, H.C.J.M., Voest, E.E., de Graeff, A., 2007. Symptom Prevalence in Patients with Incurable Cancer: A Systematic Review. J Pain Symptom Manage. 34(1): 94–104. https://doi.org/10.1016/j.jpainsymman.2006.10.015.

Todd, A.M.H., Laird, B.J.A., Boyle, D., Boyd, A.C., Colvin, L.A., Fallon, M.T., 2009. A Systematic Review Examining the Literature on Attitudes of Patients with Advanced Cancer Toward Research. J Pain Symptom Manage. 37(6): 1078–1085. https://doi.org/10.1016/j.jpainsymman.2008.07.009.

van Oorschot, B., Hausmann, C., Köhler, N., Leppert, K., Schweitzer, S., Steinbach, K., Anselm, R., 2004. Patienten als Partner in der letzten Lebensphase: Erste Ergebnisse und Perspektiven eines Modellvorhabens. Bundesgesundheitsbl. 47, 992–999. https://doi.org/10.1007/s00103-004-0906-4.

Vanbutsele, G., Van Belle S., Surmont V., De Laat M., Colman R., Eecloo K., Naert E., De Man M., Geboes K., Deliens L., Pardon K., 2020. The effect of early and systematic integration of palliative care in oncology on quality of life and health care use near the end of life: A randomised controlled trial. Eur J Cancer 124: 186-193. https://doi.org/10.1016/j.ejca.2019.11.009.

Vanbutsele, G., Pardon, K., Van Belle, S., Surmont, V., De Laat, M., Colman, R., Eecloo, K., Cocquyt, V., Geboes, K., Deliens, L., 2018. Effect of early and systematic integration of palliative care in patients with advanced cancer: a randomised controlled trial. Lancet Oncol. 19(3): 394–404. https://doi.org/10.1016/S1470-2045(18)30060-3.

Vehling, S., Koch, U., Ladehoff, N., Schön, G., Wegscheider, K., Heckl, U., Weis, J., Mehnert, A., 2012. Prävalenz affektiver und Angststörungen bei Krebs: Systematischer Literaturreview und Metaanalyse. Psychother Psychosom Med Psychol. 62(07): 249-258. https://doi.org/10.1055/s-0032-1309032.

Ventura, A.D., Burney, S., Brooker, J., Fletcher, J., Ricciardelli, L., 2014. Home-based palliative care: A systematic literature review of the self-reported unmet needs of patients and carers. Palliat Med. 28(5): 391–402. https://doi.org/10.1177/0269216313511141.

Wadhwa, D., Burman, D., Swami, N., Rodin, G., Lo, C., Zimmermann, C., 2013. Quality of life and mental health in caregivers of outpatients with advanced cancer. Psychooncology. 22(2): 403–410. https://doi.org/10.1002/pon.2104.

Walsh, D., Donnelly, S., Rybicki, L., 2000. The symptoms of advanced cancer: relationship to age, gender, and performance status in 1,000 patients. Support Care Cancer. 8(3): 175–179. https://doi.org/10.1007/s005200050281.

Wang, T., Molassiotis, A., Chung, B.P.M., Tan, J.-Y., 2018. Unmet care needs of advanced cancer patients and their informal caregivers: a systematic review. BMC Palliat Care. 17(1): 96. https://doi.org/10.1186/s12904-018-0346-9.

Wentlandt, K., Krzyzanowska, M.K., Swami, N., Rodin, G.M., Le, L.W., Zimmermann, C., 2012. Referral Practices of Oncologists to Specialized Palliative Care. J Clin Oncol. 30(35): 4380–4386. https://doi.org/10.1200/JCO.2012.44.0248.

WHO, 2002. WHO Definition of Palliative Care, World Health Organ. [online] URL http://www.who.int/cancer/palliative/definition/en/ [accessed 25.8.21].

Wiese, C.H.R., Zausig, Y.A., Vormelker, J., Orso, S., Graf, B.M., Hanekop, G.G., 2010. Ambulante und stationäre palliativmedizinische Patientenversorgung in Deutschland: Vergleich zur notfallmedizinischen Infrastruktur. Anaesthesist 59: 162–170. https://doi.org/10.1007/s00101-009-1651-8.

Zimmermann, C., Riechelmann, R., Krzyzanowska, M., Rodin, G., Tannock, I., 2008. Effectiveness of Specialized Palliative Care: A Systematic Review. JAMA. 299(14): 1698-1709. https://doi.org/10.1001/jama.299.14.1698.

Zimmermann, C., Swami, N., Krzyzanowska, M., Hannon, B., Leighl, N., Oza, A., Moore, M., Rydall, A., Rodin, G., Tannock, I., Donner, A., Lo, C., 2014. Early palliative care for patients with advanced cancer: a cluster-randomised controlled trial. Lancet 383(9930): 1721–1730. https://doi.org/10.1016/S0140-6736(13)62416-2.

Zimmermann, C., Swami, N., Krzyzanowska, M., Leighl, N., Rydall, A., Rodin, G., Tannock, I., Hannon, B., 2016. Perceptions of palliative care among patients with advanced cancer and their caregivers. CMAJ. 188(10): E217–E227. https://doi.org/10.1503/cmaj.151171.

Züll, C., 2015. Berufscodierung. Mannheim, GESIS – Leibniz Institut für Sozialwissenschaften (SDM – Survey Guidelines). https://doi.org/ 10.15465/sdm-sg_019.

Danksagung

Hiermit möchte ich mich sehr herzlich bedanken:

bei Prof. Dr. Karin Oechsle, meiner Doktormutter, für die Überlassung dieses spannenden Themas und die bereitwillige wissenschaftliche Betreuung, sowie die vielen Ratschläge und Korrekturen.

bei Anneke Ulrich, meiner Betreuerin, für die unermüdliche Unterstützung, sowohl wissenschaftlich als auch menschlich, ihre wegweisenden Ideen und die geduldige Beantwortung meiner vielen Fragen. Vielen lieben Dank für die gute Zusammenarbeit!

beim Team der Palliativstation des Universitätsklinikums Hamburg-Eppendorf (UKE) unter der damaligen pflegerischen Leitung von Cornelia Hlawatsch, insbesondere den Pflegekräften für ihre Unterstützung bei der Durchführung der Befragungen, sowie den Teams der anderen teilnehmenden Studienzentren:

- „Das Palliativteam", Hamburg, PalliativPartner Hamburg GbR und Palliativnetz Hamburg-West e.V. (SAPV-Teams)
- Agaplesion Diakonieklinikum Hamburg und Asklepios Westklinikum Hamburg (Palliativstationen).

bei Prof. Dr. phil. Holger Schulz und Dr. phil. Frank Schulz-Kindermann vom Institut und Poliklinik für Medizinische Psychologie, UKE, Mitglieder des wissenschaftlichen Studienteams.

bei Maria Wögens, Studienassistentin, und den wissenschaftlichen Hilfskräften Mareike Ahrenholz, Robin Tracht und Yarie Gruhl für die tatkräftige Unterstützung bei der zeitintensiven Erhebung und Eingabe der Daten.

bei Maria Stark, wissenschaftliche Mitarbeiterin des Instituts für Medizinische Biometrie und Epidemiologie, UKE, für ihren Input bei der statistischen Auswertung.

bei den anderen Promovierenden des Bereichs Palliativmedizin, UKE, für die anregenden Diskussionen im Doktoranden-Kolloquium.

Mein ganz besonderer Dank gilt den Patient:innen und ihren Angehörigen! Ich danke ihnen insbesondere für ihre Offenheit in vielen Gesprächen, die mich weit über diese Promotion hinaus prägen werden.

Außerdem bedanke ich mich von ganzem Herzen bei meinen Eltern Christiane Talke-Messerer und Bernd Messerer, meinen Geschwistern Franziska und Florian Messerer und meinen Großeltern Gisela und Hartmut Talke für die vielen Ratschläge und die großartige Unterstützung bei der Anfertigung dieser Dissertationsschrift. Und darüber hinaus bei meinem Lebenspartner Ansgar Taschinski für seine Geduld und sein Vertrauen!

Lebenslauf

Lebenslauf wurde aus datenschutzrechtlichen Gründen entfernt.

Eidesstattliche Erklärung

Ich versichere ausdrücklich, dass ich die Arbeit selbständig und ohne fremde Hilfe verfasst, andere als die von mir angegebenen Quellen und Hilfsmittel nicht benutzt und die aus den benutzten Werken wörtlich oder inhaltlich entnommenen Stellen einzeln nach Ausgabe (Auflage und Jahr des Erscheinens), Band und Seite des benutzten Werkes kenntlich gemacht habe.

Ferner versichere ich, dass ich die Dissertation bisher nicht einem Fachvertreter an einer anderen Hochschule zur Überprüfung vorgelegt oder mich anderweitig um Zulassung zur Promotion beworben habe.

Ich erkläre mich einverstanden, dass meine Dissertation vom Dekanat der Medizinischen Fakultät mit einer gängigen Software zur Erkennung von Plagiaten überprüft werden kann.

Unterschrift: ....

Appendix

List of Appendices:

Appendix 1: Specified primary diseases of participating patients

N=425	n	%
Malignant diseases (Cancer)	**389**	**91.5**
Respiratory, intrathoracic	77	18.1
Urogenital including prostata	58	13.6
Other gastrointestinal (e.g., liver, bile, pancreas)	45	10.6
Female genital organs other than breast	40	9.4
Breast	39	9.2
Lower gastrointestinal (colon, anal)	35	8.2
Upper gastrointestinal (esophagus, stomach)	24	5.6
Lymphatic, hematopoietic, and related tissue	19	4.5
Head and neck	11	2.6
Central nervous system, eye	11	2.6
Melanoma, skin	10	2.4
Sarcomas, soft tissue	5	1.2
Bones, articular cartilage	3	0.7
Other malignancies	9	2.1
Undifferentiated malignancy	3	0.7
Non-malignant diseases	**36**	**8.5**
Neurological	3	0.7
Cardiovascular	13	3.1
Pneumological	12	2.8
Other internal diseases	5	1.2
Geriatric (including dementia)	0	0
Other non-malignancies	3	0.7

Abbreviations: n= number of patients, %= valid percent.

Appendix 2: Occupational status of participating patients

Methods

The recommendations of GESIS are followed (Züll, 2015). The encoding of occupations to the International Standard Classification of Occupations 2008 (ISCO-08) is done manually using the German version of the Swiss Federal Statistical Office. Then the assignment to the Standard International Occupational Prestige Scale (SIOPS) and the International Socio-Economic Index of occupational status (ISEI-08) using SPSS syntax modules is performed (Züll, 2015). These are instruments for the international comparison. Based on the classification of Hoffmeyer-Zlotnik (2003) the SIOPS index ranks were then linked to the respective levels of autonomy of action (Ganzeboom and Treiman, 2003; Hoffmeyer-Zlotnik and Warner, 2011).

The Standard International Occupational Prestige Scale (SIOPS) was designed by Ganzeboom and Treiman. The standardized prestige scale allows for an estimate of the professional prestige hierarchy in different countries. Based on survey answers from 55 countries a scale was developed to assess and rank job titles based on their social standing. This allowed for the development of a prestige measuring scale so that each prestige value can be assigned to a corresponding ISO-coded occupational statement (Ganzeboom, 2010; Ganzeboom et al., 1992; Hoffmeyer-Zlotnik and Warner, 2011). The ISEI index (International Socio-Economic Index of occupational status), originally developed by Ganzeboom (2010), makes an international comparison of socio-economic status possible. It is based on information about the income, education, and profession of about 74,000 men working full-time using the assumption of different jobs requiring different levels of education and therefore different levels of financial compensation (Ganzeboom, 2010; Ganzeboom et al., 1992; Hoffmeyer-Zlotnik and Warner, 2011).

Results

	n	N	% (abs.)	% (rel.)	M	Md	SD	Min	Max
Information on occupation usable		339	79.8						
Yes	313		73.6	92.3					
No	26		6.1	7.7					
Occupational Prestige (SIOPS)		313	73.6		45.2	42.2	12.5	17	78
very low autonomy of action, SIOPS <32	29		6.8	9.3					
low autonomy of action, SIOPS 33-41	118		27.8	37.7					
limited autonomy of action, SIOPS 42-50	59		13.9	18.8					
advanced autonomy of action, SIOPS 51-63	75		17.6	24.0					
high autonomy of action, SIOPS >64	32		7.5	10.2					
Socio-economic Status (ISEI)		313	73.6		51.8	50.4	19.0	15	89

Abbreviations: abs. = absolute, M = Mean, Max = Maximum, Md = Median, Min = Minimum, N= data available, n= number of patients, % = percent, rel. = relative, SD = standard deviation.

Appendix 3: Psychosocial distress of severely and terminally ill patients in terms of age, gender, and type of care

a) Comparison of mean distress

N=413[a]	M (SD)	t	df	p	U[c]	p
Age (n=413)						
<72 years (n=205)	7.2 (2.2)	-0.555 [b]	411	.579	20641.0	.571
≥72 years (n=208)	7.3 (2.1)					
Gender (n=412)						
male (n=212)	7.0 (2.2)	-1.938 [b]	410	.053	18892.5	.053
female (n=200)	7.4 (2.1)					
SPC (n=413)						
SAPV (n=278)	7.2 (2.1)	-0.367 [b]	411	.714	17943.5	.465
PCU (n=135)	7.3 (2.3)					

[a] *Included: 413 patients, who had a valid score in the DT.*

[b] *Variance homogeneity fulfilled (Levene's-test not significant)*

[c] *Mann-Whitney-U-test for testing error probability if assumption for standard distribution not fulfilled*

Adjusted P-value p <.017 after Bonferroni correction due to multiple tests.

Abbreviations: df = degrees of freedom, DT = distress thermometer, M = mean, N = data available n= number of patients, PCU = palliative care unit, % = valid percent, p = probability of type I error, SAPV = specialist outpatient palliative care, SPC = specialist palliative care, t = t-test, U = Mann–Whitney U test.

b) Comparison of distress frequencies

N=413 [a]	Psychosocial distress (DT ≥5)				High psychosocial distress (DT≥8)			
	n (%)	χ	df	p	n (%)	χ	df	p
Age (n=413)								
<72 years (n=205)	180 (87.8%)	1.016	1	.313	103 (50.2%)	0.862	1	.353
≥72 years (n=208)	189 (90.9%)				114 (54.8%)			
Gender (n=412)								
male (n=212)	187 (88.2%)	0.567	1	.451	104 (49.1%)	1.989	1	.158
female (n=200)	181 (90.5%)				112 (56.0%)			
SPV (n=413)								
SAPV (n=278)	249 (89.6%)	0.044	1	.834	141 (50.7%)	1.133	1	.287
PCU (n=135)	120 (88.9%)				76 (56.7%)			

[a] *Included: 413 patients who had a valid score in the DT.*

Adjusted P-value p <.017 after Bonferroni correction due to multiple tests.

Abbreviations: χ= chi^2-test, df = degrees of freedom, DT = distress thermometer, N = data available n = number of patients, PCU = palliative care unit, % = valid percent, p = probability of type I error (chi^2-test), SAPV = specialist outpatient palliative care, SPC = specialist palliative care.

Appendix 4: Number of problems in terms of age, gender, and type of care

N=417 [a]	M (SD)	t	df	p	U[d]	p
Age (n=417)						
<72 years (n=206)	15.2 (5.8)	2.458[c]	406.592	**.014***	-	-
≥72 years (n=211)	13.8 (5.2)					
Gender (n=416)						
male (n=220)	14.2 (5.7)	-1.114[b]	414	.266	-	-
female (n=196)	14.8 (5.3)					
SPC (n=417)						
SAPV (n=278)	14.4 (5.8)	-0.298[c]	322.544	.766	-	-
PCU (n=139)	14.6 (4.9)					

Tool: DT-problem list. Significant group differences are marked in bold. Adjusted P-value p <.017 after Bonferroni correction due to multiple tests.

[a] *Included: 417 patients, who answered at least 50% of the DT-problem list.*

[b] *Variance homogeneity fulfilled (Levene's-test not significant).*

[c] *Variance homogeneity not fulfilled (Levene's-test significant), instead Welch-test.*

[d] *Mann-Whitney-U-test for testing error probability if assumption for standard distribution not fulfilled*

- assumption for standard distribution fulfilled.

Abbreviations: df = degrees of freedom, DT = distress thermometer, M = mean, N = data available, n = number of patients, PCU = palliative care unit, % = valid percent, p = probability of type I error, SAPV = specialist outpatient palliative care, SPC = specialist palliative care, t = t-test, U = Mann–Whitney U test.

Appendix 5: Group comparison of problems in regard to age (DT)

		<72 yrs.	**≥72 yrs.**			
	Ñ[a]	[n/N (%)]	[n/N (%)]	χ[b]	df	p
Practical problems						
Housing	412	64/203 (31.5%)	50/209 (23.9%)	2.975	1	.085
Insurance / financial	408	27/201 (13.4%)	18/207 (8.7%)	2.332	1	.127
Work / school	413	18/203 (8.9%)	2/210 (1.0%)	14.031	1	**<.001***
Transportation	401	57/198 (28.8%)	67/203 (33.0%)	0.834	1	.361
Childcare	414	2/203 (1.0%)	0/211 (0.0%)	-	-	.240[c]
Family problems						
Dealing with partner	414	24/203 (11.8%)	8/211 (3.8%)	9.357	1	**.002***
Dealing with children	408	22/199 (11.1%)	13/209 (6.2%)	3.039	1	.081
Emotional problems						
Worry	406	141/203 (69.5%)	117/203 (57.6%)	6.124	1	**.013***
Fears	405	135/201 (67.2%)	115/204 (56.2%)	4.991	1	.025
Sadness	405	137/200 (68.5%)	113/205 (55.1%)	7.669	1	**.006***
Depression	397	78/198 (39.4%)	55/199 (27.6%)	6.157	1	**.013***
Nervousness	403	79/200 (39.5%)	85/203 (41.9%)	0.235	1	.628
Loss of interest in usual activities	400	107/200 (53.5%)	115/200 (57.5%)	0.648	1	.421
Spiritual / religious concerns						
Loss of faith	384	11/186 (5.9%)	20/198 (10.1%)	2.266	1	.132
Relating to God	383	15/186 (8.1%)	18/197 (9.1%)	0.140	1	.709
Physical problems						
Pain	417	158/206 (76.7%)	160/211 (75.8%)	0.044	1	.835
Nausea	408	115/202 (56.9%)	110/206 (53.4%)	0.515	1	.473
Fatigue	413	186/202 (92.1%)	195/211 (92.4%)	0.016	1	.898
Sleep	409	118/203 (58.1%)	113/206 (54.9%)	0.446	1	.504

	Ñ [a]	**<72 yrs.** [n/N (%)]	**≥72 yrs.** [n/N (%)]	χ [b]	df	p
Getting around	413	187/205 (91.2%)	187/208 (89.9%)	0.209	1	.648
Bathing/ Dressing	404	135/203 (66.5%)	135/201 (67.2%)	0.020	1	.888
Appearance	397	99/198 (50.0%)	78/199 (39.2%)	4.689	1	.030
Breathing	406	109/201 (54.2%)	124/205 (60.5%)	1.626	1	.202
Mouth sores	408	62/203 (30.5%)	52/205 (25.4%)	1.357	1	.244
Eating	402	137/201 (68.2%)	137/201 (68.2%)	0.000	1	1.000
Indigestion	411	126/203 (62.1%)	134/208 (64.4%)	0.245	1	.621
Constipation	408	98/202 (48.5%)	109/206 (52.9%)	0.789	1	.374
Diarrhea	407	53/200 (26.5%)	47/207 (22.7%)	0.790	1	.374
Changes in urination	407	73/203 (36.0%)	74/204 (36.3%)	0.004	1	.947
Fevers	410	22/204 (10.8%)	15/206 (7.3%)	1.532	1	.216
Skin dry / itchy	409	103/203 (50.7%)	100/206 (48.5%)	0.197	1	.657
Nose dry / congested	406	75/201 (37.3%)	68/205 (33.2%)	0.763	1	.382
Tingling in hands/feet	408	92/203 (45.3%)	81/205 (39.5%)	1.409	1	.235
Feeling swollen	407	83/202 (41.1%)	70/205 (34.1%)	2.090	1	.148
Memory / concentration	409	102/204 (50.0%)	98/205 (47.8%)	0.197	1	.657
Sexual problems	388	73/193 (37.8%)	36/195 (18.5%)	18.001	1	**<.001***
Other problems	379	5/186 (2.7%)	9/193 (4.7%)	1.039	1	.308

Significant group differences are marked in bold. Tool: DT-problem list. Adjusted P-value p < .017 after Bonferroni correction due to multiple tests.

[a] *Patients who answered the specific item and completed at least 50% of the items indicated in the DT-problem list*

[b] *Chi^2-Test*

[c] *Fisher's Exact Test*

Abbreviations: df = degrees of freedom, DT = Distress-Thermometer, Ñ = number of patients included in analysis, N = total number of patients who answered the item, n = number of patients who confirmed the item, p = probability of type I error, % = valid percent.

Appendix 6: Group comparison of problems in regard to gender (DT)

	Ñ [a]	**Male** [n/N (%)]	**Female** [n/N (%)]	χ^b	df	p
Practical problems						
Housing	411	62/218 (28.4%)	51/193 (26.4%)	0.209	1	.648
Insurance / financial	407	30/215 (14.0%)	14/192 (7.3%)	4.668	1	.031
Work / school	412	11/218 (5.0%)	8/194 (4.1%)	0.198	1	.656
Transportation	400	68/211 (32.2%)	55/ 189 (29.1%)	0.458	1	.499
Childcare	413	0/219 (0.0%)	2/194 (1.0%)	-	-	.220[c]
Family problems						
Dealing with partner	413	15/218 (6.9%)	17/195 (8.7%)	0.486	1	.486
Dealing with children	407	15/214 (7.0%)	20/193 (10.4%)	1.452	1	.228
Emotional problems						
Worry	405	124/215 (57.7%)	133/190 (70.0%)	6.608	1	**.010***
Fears	404	118/215 (54.9%)	131/189 (69.3%)	8.855	1	**.003***
Sadness	404	112/214 (52.3%)	137/190 (72.1%)	16.633	1	**<.001***
Depression	396	68/214 (31.8%)	64/182 (35.2%)	0.508	1	.476
Nervousness	402	76/216 (35.2%)	87/186 (46.8%)	5.568	1	.018
Loss of interest in usual activities	399	116/212 (54.7%)	105/187 (56.1%)	0.083	1	.774
Spiritual / religious concerns						
Loss of faith	383	16/203 (7.9%)	15/180 (8.3%)	0.026	1	.872
Relating to God	382	13/203 (6.4%)	20/179 (11.2%)	2.741	1	.098
Physical problems						
Pain	416	162/220 (73.6%)	155/196 (79.1%)	1.695	1	.193
Nausea	407	101/217 (46.5%)	123/190 (64.7%)	13.549	1	**<.001***
Fatigue	412	201/217 (92.6%)	179/195 (91.8%)	0.099	1	.753
Sleep	408	130/216 (60.2%)	100/192 (52.1%)	2.713	1	.100

	Ñ [a]	**Male** [n/N (%)]	**Female** [n/N (%)]	χ^b	df	p
Getting around	412	201/218 (92.2%)	172/194 (88.7%)	1.503	1	.220
Bathing / Dressing	403	145/216 (67.1%)	124/187 (66.3%)	0.030	1	.862
Appearance	396	85/211 (40.3%)	91/185 (49.2%)	3.166	1	.075
Breathing	405	132/211 (62.6%)	100/194 (51.5%)	5.010	1	.025
Mouth sores	407	63/218 (28.9%)	50/189 (26.5%)	0.302	1	.583
Eating	401	142/213 (66.7%)	131/188 (69.7%)	0.417	1	.518
Indigestion	410	128/218 (58.7%)	131/192 (68.2%)	3.971	1	.046
Constipation	407	99/218 (45.4%)	107/189 (56.6%)	5.081	1	.024
Diarrhea	406	50/215 (23.3%)	50/191 (26.2%)	0.465	1	.495
Changes in urination	406	85/216 (39.4%)	62/190 (32.6%)	1.976	1	.160
Fevers	409	28/217 (12.9%)	9/192 (4.7%)	8.357	1	**.004***
Skin dry / itchy	408	112/216 (51.9%)	90/192 (46.9%)	1.007	1	.316
Nose dry / congested	405	69/216 (31.9%)	74/189 (39.2%)	2.293	1	.130
Tingling in hands / feet	407	86/216 (39.8%)	87/191 (45.5%)	1.364	1	.243
Feeling swollen	406	70/216 (32.4%)	83/190 (43.7%)	5.474	1	.019
Memory / concentration	408	109/217 (50.2%)	90/191 (47.1%)	0.393	1	.531
Sexual problems	387	78/206 (37.9%)	31/181 (17.1%)	20.478	1	**<.001***
Other problems	417	6/206 (2.9%)	10/211 (4.7%)	0.943	1	.332

Significant group differences are marked in bold. Tool: DT-problem list. Adjusted P-value p <.017 after Bonferroni correction due to multiple tests.

[a] *Patients who answered the specific item and completed at least 50% of the items indicated in the DT-problem list*

[b] *Chi^2-Test*

[c] *Fisher's Exact Test*

Abbreviations: df = degrees of freedom, DT = Distress-Thermometer, Ñ = number of patients included in analysis, N = total number of patients who answered the item, n = number of patients who confirmed the item, p = probability of type I error, % = valid percent.

Appendix 7: Group comparison of problems in regard to type of care (DT)

	Ñ[a]	SAPV [n/N (%)]	PCU [n/N (%)]	χ[b]	df	p
Practical problems						
Housing	412	81/275 (29.5%)	33/137 (24.1%)	1.316	1	.251
Insurance/financial	408	35/275 (12.7%)	10/133 (7.5%)	2.478	1	.115
Work / school	413	13/275 (4.7%)	7/138 (5.1%)	0.024	1	.877
Transportation	401	94/269 (34.9%)	30/132 (22.7%)	6.187	1	**.013***
Childcare	414	1/277 (0.4%)	1/137 (0.7%)	-	-	.553[c]
Family problems						
Dealing with partner	414	27/276 (9.8%)	5/138 (3.6%)	4.894	1	.027
Dealing with children	408	22/272 (8.1%)	13/136 (9.6%)	0.250	1	.617
Emotional problems						
Worry	406	172/270 (63.7%)	86/136 (63.2%)	0.009	1	.926
Fears	405	170/271 (62.7%)	80/134 (59.7%)	0.348	1	.555
Sadness	405	161/270 (59.6%)	89/135 (65.9%)	1.510	1	.219
Depression	397	92/262 (35.1%)	41/135 (30.4%)	0.900	1	.343
Nervousness	403	109/269 (40.5%)	55/134 (41.0%)	0.010	1	.920
Loss of interest in usual activities	400	151/267 (56.6%)	71/133 (53.4%)	0.361	1	.548
Spiritual / religious concerns						
Loss of faith	384	24/256 (9.4%)	7/128 (5.5%)	1.755	1	.185
Relating to God	383	25/256 (9.8%)	8/127 (6.3%)	1.295	1	.255
Physical problems						
Pain	417	215/278 (77.3%)	103/139 (74.1%)	0.536	1	.464
Nausea	408	145/272 (53.3%)	80/136 (58.8%)	1.115	1	.291
Fatigue	413	253/274 (92.2%)	128/139 (92.1%)	0.008	1	.929
Sleep	409	156/273 (57.1%)	75/136 (55.1%)	0.147	1	.701

	Ñ [a]	SAPV [n/N (%)]	PCU [n/N (%)]	χ^b	df	p
Getting around	413	253/275 (92.0%)	121/138 (87.7%)	2.004	1	.157
Bathing / Dressing	404	181/269 (67.3%)	89/135 (65.9%)	0.075	1	.784
Appearance	397	128/268 (47.8%)	49/129 (38.0%)	3.369	1	.066
Breathing	406	147/273 (53.8%)	86/133 (64.7%)	4.278	1	.039
Mouth sores	408	76/273 (27.8%)	38/135 (28.1%)	0.004	1	.948
Eating	402	192/270 (71.1%)	82/132 (62.1%)	3.302	1	.069
Indigestion	411	177/276 (64.1%)	83/135 (61.5%)	0.274	1	.601
Constipation	408	133/270 (49.3%)	74/138 (53.6%)	0.696	1	.404
Diarrhea	407	68/271 (25.1%)	32/136 (23.5%)	0.119	1	.730
Changes in urination	407	94/271 (34.7%)	53/136 (39.0%)	0.720	1	.396
Fevers	410	18/273 (6.6%)	19/137 (13.9%)	5.881	1	**.015***
Skin dry / itchy	409	131/272 (48.2%)	72/137 (52.6%)	0.703	1	.402
Nose dry / congested	406	84/270 (31.1%)	59/136 (43.4%)	5.969	1	**.015***
Tingling in hands / feet	408	98/269 (36.4%)	75/139 (54.0%)	11.525	1	.001
Feeling swollen	407	87/274 (31.8%)	66/133 (49.6%)	12.191	1	**<.001***
Memory / concentration	409	127/275 (46.2%)	73/134 (54.5%)	2.481	1	.115
Sexual problems	388	73/260 (28.1%)	36/128 (28.1%)	0.000	1	.992
Other problems	417	2/278 (0.7%)	14/139 (10.1%)	21.968	1	**<.001***

Significant group differences are marked in bold. Tool: DT-problem list. Adjusted P-value p < .017 after Bonferroni correction due to multiple tests.

[a] Patients who answered the specific item and completed at least 50% of the items indicated in the DT-problem list

[b] Chi²-Test

[c] Fisher's Exact Test

Abbreviations: df = degrees of freedom, DT = Distress-Thermometer, Ñ = number of patients included in analysis, N = total number of patients who answered the item, n = number of patients who confirmed the item, SAPV = specialist outpatient palliative care, p = probability of type I error, PCU=palliative care unit, % = valid percent.

Appendix 8: Comparison of problems in regard to age (PNPC-sv)

	Ñ [a]	**<72 years** [n/N (%)]	**≥72 years** [n/N (%)]	χ [b]	df	p
Daily activities						
Personal transportation (cycling, driving a car, using public transportation, etc.)	409	133/202 (65.8%)	157/207 (75.8%)	4.959	1	.026
Doing light housework (tidying up, etc.)	408	174/201 (86.6%)	192/207 (92.8%)	4.226	1	.040
Body care, washing, dressing, or toilet	405	165/201 (82.1%)	174/204 (85.3%)	0.762	1	.383
Autonomy						
Difficulties in continuing the usual activities	408	181/201 (90.0%)	187/207 (90.3%)	0.010	1	.922
Being dependent on others	404	111/198 (56.1%)	115/206 (55.8%)	0.002	1	.962
Experiencing loss of control over one's life	411	169/202 (83.7%)	174/209 (83.3%)	0.012	1	.911
Difficulties to give tasks out of hands	404	142/199 (71.4%)	123/205 (60.0%)	5.771	1	**.016***
Social issues						
Finding it difficult to talk about the disease, because of not wanting to burden others	406	48/200 (24.0%)	35/206 (17.0%)	3.006	1	.080
Finding others not receptive to talking about the disease	407	70/201 (34.8%)	55/206 (26.7%)	3.157	1	.076
Difficulties in finding someone to talk to (confidant)	402	115/199 (57.8%)	102/203 (50.2%)	2.301	1	.129
Difficulties in talking about the disease with life companion	408	76/199 (38.2%)	74/209 (35.4%)	0.340	1	.560
Problems in relationship with life companion	409	63/200 (31.5%)	81/209 (38.8%)	2.359	1	.125
Psychological issues						
Fear of progression of the disease	410	103/201 (51.2%)	81/209 (38.8%)	6.459	1	**.011***
Difficulty coping with the unpredictability of the future	411	166/202 (82.2%)	171/209 (81.8%)	0.009	1	.924
Difficulties to show emotions	403	151/201 (75.1%)	132/202 (65.3%)	4.606	1	.032
Depressed mood	410	111/202 (55.0%)	100/208 (48.1%)	1.938	1	.164
Spiritual issues						
Difficulties to be of avail for others	408	99/201 (49.3%)	103/207 (49.8%)	0.010	1	.919
Difficulties to accept the disease	404	113/200 (56.5%)	118/204 (57.8%)	0.074	1	.785
Difficulties to be engaged usefully	404	97/199 (48.7%)	95/205 (46.3%)	0.234	1	.629

	Ñ [a]	**<72 years** [n/N (%)]	**≥72 years** [n/N (%)]	χ [b]	df	p
Difficulties concerning the meaning of death	411	111/202 (55.0%)	119/209 (56.9%)	0.165	1	.685
Financial problems						
Extra expenditures because of the disease	407	73/201 (36.3%)	49/206 (23.8%)	7.612	1	**.006***
Loss of income because of the disease	405	56/201 (27.9%)	14/204 (6.9%)	31.224	1	**<.001***
Need of information						
Insufficient information, e.g., about the disease and its treatment, aids and agencies that can provide help	404	71/200 (35.5%)	67/204 (32.8%)	0.317	1	.573

Tool: PNPC-sv. Significant group differences are marked in bold. Adjusted P-value p < .017 after Bonferroni correction due to multiple tests.

[a] *Patients who answered the specific item and completed at least 50% of the items indicated in the PNPC-sv*

[b] *Chi^2-Test*

Abbreviations: df = degrees of freedom, DT = Distress-Thermometer, Ñ = number of patients included in analysis, N = total number of patients who answered the item, n = number of patients who confirmed the item, p = probability of type I error, % = valid percent.

Appendix 9: Comparison of problems in regard to gender (PNPC-sv)

	Ñ [a]	**Male** [n/N (%)]	**Female** [n/N (%)]	χ [b]	df	p
Daily activities						
Personal transportation (cycling, driving a car, using public transportation, etc.)	408	157/214 (73.4%)	132/194 (68.0%)	1.396	1	.237
Doing light housework (tidying up, etc.)	407	195/213 (91.5%)	170/194 (87.6%)	1.686	1	.194
Body care, washing, dressing, or toilet	404	171/210 (81.4%)	167/194 (86.1%)	1.598	1	.206
Autonomy						
Difficulties in continuing the usual activities	407	193/214 (90.2%)	174/193 (90.2%)	0.000	1	.922
Being dependent on others	403	104/209 (49.8%)	121/194 (62.4%)	6.488	1	**.011***
Experiencing loss of control over one's life	410	176/215 (81.9%)	166/195 (85.1%)	0.789	1	.374
Difficulties to give tasks out of hands	403	139/210 (66.2%)	125/193 (64.8%)	0.090	1	.764
Social issues						
Finding it difficult to talk about the disease, because of not wanting to burden others	405	49/214 (22.9%)	33/191 (17.3%)	1.974	1	.160
Finding others not receptive to talking about the disease	406	71/213 (33.3%)	53/193 (27.5%)	1.646	1	.200
Difficulties in finding someone to talk to (confidant)	401	117/212 (55.2%)	99/189 (52.4%)	0.317	1	.573
Difficulties in talking about the disease with life companion	407	80/212 (37.7%)	69/195 (35.4%)	0.242	1	.623
Problems in relationship with life companion	408	87/215 (40.5%)	56/193 (29.0%)	5.857	1	**.016***
Psychological issues:						
Fear of progression of the disease	409	95/216 (44.0%)	88/193 (45.6%)	0.107	1	.743
Difficulty coping with the unpredictability of the future	410	174/215 (80.9%)	162/195 (83.1%)	0.319	1	.572
Difficulties to show emotions	402	142/212 (67.0%)	140/190 (73.7%)	2.150	1	.143
Depressed mood	409	120/214 (56.1%)	91/195 (46.7%)	3.616	1	.057
Spiritual issues						
Difficulties to be of avail for others	407	103/215 (47.9%)	98/192 (51.0%)	0.399	1	.528
Difficulties to accept the disease	403	122/214 (57.0%)	108/189 (57.1%)	0.001	1	.978
Difficulties to be engaged usefully	403	100/212 (47.2%)	91/191 (47.6%)	0.009	1	.924

	Ñ [a]	**Male** [n/N (%)]	**Female** [n/N (%)]	χ [b]	df	p
Difficulties concerning the meaning of death	410	118/215 (54.9%)	111/195 (56.9%)	0.172	1	.678
Financial problems						
Extra expenditures because of the disease	406	62/212 (29.2%)	60/194 (30.9%)	0.136	1	.712
Loss of income because of the disease	404	36/212 (17.0%)	34/192 (17.7%)	0.037	1	.847
Need of information						
Insufficient information, e.g., about the disease and its treatment, aids and agencies that can provide help	403	75/213 (35.2%)	62/190 (32.6%)	0.298	1	.585

Tool: PNPC-sv. Significant group differences are marked in bold. Adjusted P-value p < .017 after Bonferroni correction due to multiple tests.

[a] *Patients who answered the specific item and completed at least 50% of the items indicated in the PNPC-sv*

[b] *Chi^2-Test*

Abbreviations: df = degrees of freedom, DT = Distress-Thermometer, Ñ = number of patients included in analysis, N = total number of patients who answered the item, n = number of patients who confirmed the item, p = probability of type I error, % = valid percent.

Appendix 10: Comparison of problems in regard to type of care (PNPC-sv)

	Ñ [a]	SAPV [n/N (%)]	PCU [n/N (%)]	χ [b]	df	p
Daily activities						
Personal transportation (cycling, driving a car, using public transportation, etc.)	409	197/272 (72.4%)	93/137 (67.9%)	0.912	1	.340
Doing light housework (tidying up, etc.)	408	252/272 (92.6%)	114/136 (83.8%)	7.644	1	**.006***
Body care, washing, dressing, or toilet	405	236/270 (87.4%)	103/135 (76.3%)	8.146	1	**.004***
Autonomy						
Difficulties in continuing the usual activities	408	247/271 (91.1%)	121/137 (88.3%)	0.820	1	.365
Being dependent on others	404	149/269 (55.4%)	77/135 (57.0%)	0.099	1	.753
Experiencing loss of control over one’s life	411	228/273 (83.5%)	115/138 (83.3%)	0.002	1	.962
Difficulties to give tasks out of hands	404	174/270 (64.4%)	91/134 (67.9%)	0.477	1	.490
Social issues						
Finding it difficult to talk about the disease, because of not wanting to burden others	406	64/271 (23.6%)	19/135 (14.1%)	5.045	1	.025
Finding others not receptive to talking about the disease	407	92/270 (34.1%)	33/137 (24.1%)	4.259	1	.039
Difficulties in finding someone to talk to (confidant)	402	149/267 (55.8%)	68/135 (50.4%)	1.066	1	.302
Difficulties in talking about the disease with life companion	408	103/273 (37.7%)	47/135 (34.8%)	0.330	1	.566
Problems in relationship with life companion	409	100/273 (36.6%)	44/136 (32.4%)	0.728	1	.394
Psychological issues						
Fear of progression of the disease	410	128/273 (46.9%)	56/137 (40.9%)	1.332	1	.248
Difficulty coping with the unpredictability of the future	411	277/273 (83.2%)	110/138 (79.7%)	0.735	1	.391
Difficulties to show emotions	403	195/270 (72.2%)	88/133 (66.2%)	1.563	1	.211
Depressed mood	410	142/273 (52.0%)	69/137 (50.4%)	0.099	1	.753
Spiritual issues						
Difficulties to be of avail for others	408	140/271 (51.7%)	62/137 (45.3%)	1.493	1	.222
Difficulties to accept the disease	404	158/268 (59.0%)	73/136 (53.7%)	1.027	1	.311
Difficulties to be engaged usefully	404	138/269 (51.3%)	54/135 (40.0%)	4.603	1	.032

	Ñ [a]	SAPV [n/N (%)]	PCU [n/N (%)]	χ [b]	df	p
Difficulties concerning the meaning of death	411	165/274 (60.2%)	65/137 (47.4%)	6.047	1	**.014***
Financial problems						
Extra expenditures because of the disease	407	82/271 (30.3%)	40/136 (29.4%)	0.031	1	.860
Loss of income because of the disease	405	38/271 (14.0%)	32/134 (23.9%)	6.095	1	**.014***
Need of information						
Insufficient information, e.g., about the disease and its treatment, aids and agencies that can provide help	404	104/268 (38.8%)	34/136 (25.0%)	7.646	1	**.006***

Tool: PNPC-sv. Significant group differences are marked in bold. Adjusted P-value p < .017 after Bonferroni correction due to multiple tests.

[a] *Patients who answered the specific item and completed at least 50% of the items indicated in the PNPC-sv*

[b] *Chi^2-Test*

Abbreviations: df = degrees of freedom, DT = Distress-Thermometer, Ñ = number of patients included in analysis, N = total number of patients who answered the item, n = number of patients who confirmed the item, SAPV = specialist outpatient palliative care, p = probability of type I error, PCU=palliative care unit, % = valid percent.

Appendix 11: Comparison of unmet needs in regard to age (PNPC-sv)

	Ñ [a]	<72 years [n/N (%)]	≥72 years [n/N (%)]	χ [b]	df	p
Daily activities						
Personal transportation (cycling, driving a car, using public transportation, etc.)	283	45/130 (34.6%)	73/153 (47.7%)	4.959	1	.026
Doing light housework (tidying up, etc.)	352	81/169 (47.9%)	86/183 (47.0%)	0.031	1	.861
Body care, washing, dressing, or toilet	323	74/159 (46.5%)	84/164 (51.2%)	0.707	1	.400
Autonomy						
Difficulties in continuing the usual activities	346	66/171 (38.6%)	81/175 (46.3%)	2.093	1	.148
Being dependent on others	214	38/106 (35.8%)	40/108 (37.0%)	0.033	1	.857
Experiencing loss of control over one's life	321	63/160 (39.4%)	58/161 (36.0%)	0.384	1	.536
Difficulties to give tasks out of hands	253	59/134 (44.0%)	51/119 (42.9%)	0.035	1	.851
Social issues						
Finding it difficult to talk about the disease, because of not wanting to burden others	80	22/45 (48.9%)	13/35 (37.1%)	1.104	1	.293
Finding others not receptive to talking about the disease	117	33/68 (48.5%)	22/49 (44.9%)	0.151	1	.698
Difficulties in finding someone to talk to (confidant)	205	53/110 (48.2%)	42/95 (44.2%)	0.323	1	.570
Difficulties in talking about the disease with life companion	140	30/74 (40.5%)	22/66 (33.3%)	0.776	1	.378
Problems in relationship with life companion	136	37/59 (62.7%)	39/77 (50.6%)	1.971	1	.160
Psychological issues						
Fear of progression of the disease	171	47/97 (48.5%)	27/74 (36.5%)	2.449	1	.118
Difficulty coping with the unpredictability of the future	-	-	-	-	-	-
Difficulties to show emotions	265	68/142 (47.9%)	55/123 (44.7%)	0.267	1	.606
Depressed mood	199	38/104 (36.5%)	27/95 (28.4%)	1.487	1	.223
Spiritual issues						
Difficulties to be of avail for others	186	40/93 (43.0%)	38/93 (40.9%)	0.088	1	.766
Difficulties to accept the disease	214	50/105 (47.6%)	35/109 (32.1%)	5.373	1	.020
Difficulties to be engaged usefully	175	52/88 (59.1%)	41/87 (47.1%)	2.515	1	.113

	Ñ [a]	**<72 years** [n/N (%)]	**≥72 years** [n/N (%)]	χ [b]	df	p
Difficulties concerning the meaning of death	208	54/101 (53.5%)	49/107 (45.8%)	1.223	1	.269
Financial problems						
Extra expenditures because of the disease	105	43/66 (65.2%)	22/39 (56.4%)	0.794	1	.373
Loss of income because of the disease	65	33/52 (63.5%)	6/13 (46.2%)	1.298	1	.255
Need of information						
Insufficient information, e.g., about the disease and its treatment, aids and agencies that can provide help	132	56/69 (81.2%)	54/63 (85.7%)	0.492	1	.483

Tool: PNPC-sv. Significant group differences are marked in bold. Adjusted P-value p < .017 after Bonferroni correction due to multiple tests.

[a] Patients who answered the specific item and completed at least 50% of the items indicated in the PNPC-sv

[b] Chi^2-Test

Abbreviations: df = degrees of freedom, DT = Distress-Thermometer, Ñ = number of patients included in analysis, N = total number of patients who answered the item, n = number of patients who confirmed the item, p = probability of type I error, % = valid percent.

Appendix 12: Comparison of unmet needs in regard to gender (PNPC-sv)

	Ñ [a]	**Male** [n/N (%)]	**Female** [n/N (%)]	χ [b]	df	p
Daily activities						
Personal transportation (cycling, driving a car, using public transportation, etc.)	282	61/155 (39.4%)	56/127 (44.1%)	0.646	1	.422
Doing light housework (tidying up, etc.)	351	86/187 (46.0%)	80/164 (48.8%)	0.273	1	.601
Body care, washing, dressing, or toilet	322	77/163 (47.2%)	80/159 (50.3%)	0.305	1	.581
Autonomy:						
Difficulties in continuing the usual activities	345	66/181 (36.5%)	80/164 (48.8%)	5.346	1	.021
Being dependent on others	213	37/101 (36.6%)	40/112 (35.7%)	0.019	1	.889
Experiencing loss of control over one’s life	320	64/169 (37.9%)	56/151 (37.1%)	0.021	1	.885
Difficulties to give tasks out of hands	252	53/134 (39.6%)	56/118 (47.5%)	1.598	1	.206
Social issues						
Finding it difficult to talk about the disease, because of not wanting to burden others	79	17/46 (37.0%)	17/33 (51.5%)	1.661	1	.197
Finding others not receptive to talking about the disease	116	33/68 (48.5%)	21/48 (43.8%)	0.258	1	.611
Difficulties in finding someone to talk to (confidant)	204	50/113 (44.2%)	44/91 (48.4%)	0.342	1	.559
Difficulties in talking about the disease with life companion	139	25/76 (32.9%)	26/63 (41.3%)	1.040	1	.308
Problems in relationship with life companion	135	43/84 (51.2%)	32/51 (62.7%)	1.716	1	.190
Psychological issues:						
Fear of progression of the disease	170	35/92 (38.0%)	38/78 (48.7%)	1.963	1	.161
Difficulty coping with the unpredictability of the future	-	-	-	-	-	-
Difficulties to show emotions	264	57/132 (43.2%)	65/132 (49.2%)	0.975	1	.323
Depressed mood	199	37/113 (32.7%)	28/86 (32.6%)	0.001	1	.978
Spiritual issues:						
Difficulties to be of avail for others	185	40/96 (41.7%)	37/89 (41.6%)	0.000	1	.990
Difficulties to accept the disease	213	45/115 (39.1%)	39/98 (39.8%)	0.010	1	.921
Difficulties to be engaged usefully	174	45/90 (50.0%)	47/84 (56.0%)	0.618	1	.432

	Ñ [a]	**Male** [n/N (%)]	**Female** [n/N (%)]	χ [b]	df	p
Difficulties concerning the meaning of death	207	52/106 (49.1%)	50/101 (49.5%)	0.004	1	.949
Financial problems:						
Extra expenditures because of the disease	105	32/53 (60.4%)	33/52 (63.5%)	0.106	1	.745
Loss of income because of the disease.	65	18/33 (54.5%)	21/32 (65.6%)	0.831	1	.362
Need of information:						
Insufficient information, e.g., about the disease and its treatment, aids and agencies that can provide help	131	61/71 (85.9%)	46/60 (80.0%)	0.814	1	.367

Tool: PNPC-sv. Significant group differences are marked in bold. Adjusted P-value p < 0.017 after Bonferroni correction due to multiple tests.

[a] *Patients who answered the specific item and completed at least 50% of the items indicated in the PNPC-sv,*

[b] *Chi^2-Test,*

Abbreviations: df = degrees of freedom, DT = Distress-Thermometer, Ñ = number of patients included in analysis, N = total number of patients who answered the item, n = number of patients who confirmed the item, p = probability of type I error, % = valid percent.

Appendix 13: Comparison of unmet needs in regard to type of care (PNPC-sv)

	Ñ [a]	**SAPV** [n/N (%)]	**PCU** [n/N (%)]	χ [b]	df	p
Daily activities						
Personal transportation (cycling, driving a car, using public transportation, etc.)	283	95/191 (49.7%)	23/92 (25.0%)	15.631	1	**<.001***
Doing light housework (tidying up, etc.)	352	119/245 (48.6%)	48/107 (44.9%)	0.411	1	.521
Body care, washing, dressing, or toilet	323	117/227 (51.5%)	41/96 (42.7%)	2.107	1	.147
Autonomy:						
Difficulties in continuing the usual activities	346	97/232 (41.8%)	50/114 (43.9%)	0.131	1	.717
Being dependent on others	214	54/141 (38.3%)	24/73 (32.9%)	0.610	1	.435
Experiencing loss of control over one’s life	321	84/214 (39.3%)	37/107 (34.6%)	0.663	1	.415
Difficulties to give tasks out of hands	253	77/164 (47.0%)	33/89 (37.1%)	2.288	1	.130
Social issues						
Finding it difficult to talk about the disease, because of not wanting to burden others	80	29/61 (47.5%)	6/19 (31.6%)	1.500	1	.221
Finding others not receptive to talking about the disease	117	45/87 (51.7%)	10/30 (33.3%)	3.029	1	.082
Difficulties in finding someone to talk to (confidant)	205	72/142 (50.7%)	23/63 (36.5%)	3.537	1	.060
Difficulties in talking about the disease with life companion	140	43/98 (43.9%)	9/42 (21.4%)	6.346	1	**.012***
Problems in relationship with life companion	136	54/93 (58.1%)	22/43 (51.2%)	0.568	1	.451
Psychological issues:						
Fear of progression of the disease	171	57/121 (47.1%)	17/50 (34.0%)	2.476	1	.116
Difficulty coping with the unpredictability of the future	-	-	-	-	-	-
Difficulties to show emotions	265	86/182 (47.3%)	37/83 (44.6%)	0.164	1	.686
Depressed mood	199	47/131 (35.9%)	18/68 (26.5%)	1.801	1	.180
Spiritual issues:						
Difficulties to be of avail for others	186	59/129 (45.7%)	19/57 (33.3%)	2.498	1	.114
Difficulties to accept the disease	214	66/148 (44.6%)	19/66 (28.8%)	4.763	1	.029
Difficulties to be engaged usefully	175	72/129 (55.8%)	21/46 (45.7%)	1.406	1	.236

	Ñ [a]	**SAPV** [n/N (%)]	**PCU** [n/N (%)]	χ [b]	df	p
Difficulties concerning the meaning of death	208	87/154 (56.5%)	16/54 (29.6%)	11.542	1	**.001***
Financial problems:						
Extra expenditures because of the disease	105	48/72 (66.7%)	17/33 (51.5%)	2.203	1	.138
Loss of income because of the disease.	65	26/36 (72.2%)	13/29 (44.8%)	5.022	1	.025
Need of information:						
Insufficient information e.g., about the disease and its treatment, aids and agencies that can provide help	132	87/101 (86.1%)	23/31 (74.2%)	2.437	1	.119

Tool: PNPC-sv. Significant group differences are marked in bold. Adjusted P-value p <.017 after Bonferroni correction due to multiple tests.

[a] Patients who answered the specific item and completed at least 50% of the items indicated in the PNPC-sv

[b] Chi^2-Test

Abbreviations: df = degrees of freedom, DT = Distress-Thermometer, Ñ = number of patients included in analysis, N = total number of patients who answered the item, n = number of patients who confirmed the item, SAPV = specialist outpatient palliative care, p = probability of type I error, PCU = palliative care unit, % = valid percent.

Appendix 14: Group comparison of depression and anxiety in terms of age, gender, and type of care

	M (SD)	t	df	p	U^2	p
PHQ-4 (N=405)						
Age (n=405)						
<72 years (n=199)	5.7 (3.7)	1.949^1	403	.052	17944.5	.029
≥72 years (n=206)	5.0 (3.7)					
Gender (n=404)						
male (n=209)	5.0 (3.6)	-1.780^1	402	.076	18181.5	.060
female (n=195)	5.7 (3.8)					
SPC (n=405)						
SAPV (n=272)	5.4 (3.7)	0.453^1	403	.650	17580.5	.645
PCU (n=133)	5.2 (3.7)					
PHQ-2 (N=409)						
Age (n=409)						
<72 years (n=200)	3.2 (2.0)	1.797^1	407	.073	18675.5	.059
≥72 years (n=209)	2.8 (2.0)					
Gender (n=408)						
male (n=210)	2.9 (2.0)	-1.243^1	406	.215	19194.0	.174
female (n=198)	3.1 (2.0)					
SPC (n=409)						
SAPV (n=274)	3.0 (1.9)	-0.405^1	407	.686	17965.5	.633
PCU (n=135)	3.0 (2.1)					
GAD-2 (N=415)						
Age (n=415)						
<72 years (n=205)	2.5 (2.0)	1.673^1	413	.095	19228.5	.056
≥72 years (n=210)	2.2 (2.0)					
Gender (n=414)						
male (n=217)	2.2 (2.0)	-2.038^1	412	.042	18848.5	.035
female (n=197)	2.6 (2.0)					

	M (SD)	t	df	p	U[2]	p
SPC (n=415)						
SAPV (n=279)	2.5 (2.0)	1.250[1]	413	.212	17366.0	.155
PCU (n=136)	2.2 (2.0)					

[1] Variance homogeneity fulfilled (Levene's test not significant)

[2] Mann-Whitney-U-test for testing error probability if assumption for standard distribution not fulfilled

Significant group differences are marked in bold. Adjusted P-value p <.017 after Bonferroni correction due to multiple tests.

Abbreviations: df = degrees of freedom, GAD-2 = General Anxiety Disorders - Scale 2, M = median, N = number of patients included in analysis, n = number of patients, p = probability of type I error, PCU = palliative care unit, % = valid percent, PHQ-2 = Patient Health Questionnaire -Module 4, PHQ-4= Patient Health Questionnaire - Module 4, SAPV = specialist outpatient palliative care, SD = standard deviation, t = Student's t-test, U = Mann–Whitney U test.

Appendix 15: Expression of a wish by severely and terminally ill patients in terms of age, gender, and type of care

N=361[a]	**Wish** n/ (%)	**No Wish** n/ (%)	χ	df	p
Age (n=361)					
<72 years (n=162)	119 (66.1%)	61 (33.9%)	0.236	1	.627
≥72 years (n=168)	124 (68.5%)	57 (31.5%)			
Gender (n=360)					
male (n=182)	126 (69.2%)	56 (30.8%)	0.674	1	.412
female (n=178)	116 (65.2%)	62 (34.8%)			
SPC (n=361)					
SAPV (n=238)	147 (61.8%)	91 (38.2%)	9.773	1	**.002***
PCU (n=123)	96 (78.0%)	27 (22.0%)			

[a] *Included: 361 patients (85%), who answered the question of having a special wish.*

Significant group differences are marked in bold. Adjusted P-value p <.017 after Bonferroni correction due to multiple tests.

Abbreviations: df = degrees of freedom, χ = Chi^2-test, N = total number of patients who answered the item, n = number of patients who confirmed the item, PCU = palliative care unit, % = valid percent, p = probability of type I error (chi-square test), SAPV = specialist outpatient palliative care, SPC = specialist palliative care.

Appendix 16: Group comparison of potential study participants in terms of age, gender, and type of care

N=1695[a]	Overall[a]	Excluded patients		Non-participants		Participants	
	n (%)	n (%)	p^b	n (%)	p^b	n (%)	p^b
Age	N=1683	n=985		n=273		n=425	
<75 yrs.	808 (48.0%)	410 (41.6%)	***<.001****	138 (50.5%)	*,337*	260 (61.2%)	***<.001****
≥75 yrs.	875 (52.0%)	575 (58.4%)		135 (49.5%)		165 (38.8%)	
				χ (df)=46.314 (2); p<.001[c]			
Gender	N=1683	n=983		n=276		n=424	
male	836 (50.3%)	467 (47.5%)		149 (54.0%)		220 (51.9%)	
female	847 (49.7%)	516 (52.5%)	*.080*	127 (46.0%)	*,092*	204 (48.1%)	*.154*
				χ (df)=4.728 (2); p=.094[c]			
SPC	N=1695	n=990		n=280		n=425	
SAPV	821 (48.4%)	393 (39.7%)	***<.001****	143 (51.1%)	*.202*	285 (67.1%)	***<.001****
PCU	874 (51.6%)	597 (60.3%)		137 (48.9%)		140 (32.9%)	
				χ (df)=90.066 (2); p<.001[c]			

Significant group differences are marked in bold. Adjusted P-value p <.017 after Bonferroni correction due to multiple tests.

[a] *Drop-Out n=18, Questionnaire not returned or withdrawal of consent (see flow-chart of the sample size development).*

[b] *Comparison of the frequency distribution to the total distribution using binomial tests. Adjusted P-value p <0.017 after Bonferroni correction due to multiple testing.*

[c] *Comparison of general group differences using chi2-tests.*

Abbreviations: df = degrees of freedom, χ = Chi^2*-test, N = data available, n = number of patients, PCU = palliative care unit, % = valid percent, p = probability of type I error, SAPV = specialist outpatient palliative care, SPC = specialist palliative care.*

Appendix 17: Group comparison of excluded patients in terms of age, gender, and type of care

N=990 [a]		**Age**		**Gender**		**SPC**	
		<75 years	≥75 years	male	female	SAPV	PCU
Exclusion overall	N	985		983		990	
	n (%)	410 (41.6%)	575 (58.4%)	467 (47.5%)	516 (52.5%)	393 (39.7%)	597 (60.3%)
Cognitive impairment	N	477		475		481	
	n (%)	177 (37.1%)	300 (62.9%)	224 (47.2%)	251 (52.8%)	212 (44.1%)	269 (55.9%)
	p [b]	*.025*			*.459*	*.028*	
Physical or psychological limitation	N	119		119		119	
	n (%)	47 (39.5%)	72 (59.5%)	58 (48.7%)	61 (51.3%)	47 (39.5%)	72 (60.5%)
	p [b]	*.356*			*.428*	*.522*	
Insufficient knowledge of German	N	109		109		109	
	n (%)	76 (69.7%)	33 (30.3%)	51 (46.8%)	58 (53.2%)	66 (60.6%)	43 (39.4%)
	p [b]	***<.001***			*.480*	***<.001***	
Dying or deceased within recruitment period	N	188		187		188	
	n (%)	61 (32.4%)	127 (67.6%)	96 (51.3%)	91 (48.7%)	37 (19.7%)	151 (80.3%)
	p [b]	***.006***			*.164*	***<.001***	
Not informed within the recruitment period	N	78		78		78	
	n (%)	42 (53.8%)	36 (46.2%)	34 (43.6%)	44 (56.4%)	20 (25.6%)	58 (74.4%)
	p [b]	*.019*			*.282*	***.007***	
Other	N	14		15		15	
	n (%)	7 (50.0%)	7 (50.0%)	4 (26.7%)	11 (73.3%)	11 (73.3%)	4 (26.7%)
χ(df) [c]		*86.646 (5);* ***p<.001***		*4.311 (5); p<.506*		*51.366 (5);* ***p<.001***	

Significant group differences are marked in bold. Adjusted P-value p < 0.017 after Bonferroni correction due to multiple testing.

[a] *Drop-Out n=18, Questionnaire not returned or withdrawal of consent (see flow-chart.)*

[b] *Comparison of the frequency distribution to the total distribution using binomial tests.*

[c] *Comparison of group differences using chi*^{2}*-tests.*

Abbreviations: df = degrees of freedom, χ = Chi^2*-test, N = data available, n = number of patients, PCU = palliative care unit, % = valid percent, p = probability of type I error, SAPV = specialist outpatient palliative care, SPC = specialist palliative care.*