

Symptom assessment of the social and spiritual dimensions in hospice care patients. An exploratory mixed-method study.

Student: M.S. de Leeuw
Student number: 4295137
Version: Final
Date: 27 June 2017
Master: Utrecht University, Clinical Health Sciences, Nursing Science,
University Medical Center Utrecht
Supervisor: Everlien de Graaf, RN, MSc
Workgroup teacher: Irina Poslawsky, RN, PhD
Intern organization: Julius Center of University Medical Center Utrecht
Targeted journal: BMJ Supportive & Palliative Care
Number of words: 3745
Reporting criteria: STROBE¹ and COREQ²
Number of words Dutch abstract: 289
Number of words English abstract: 297
Reference style: Vancouver

ABSTRACT

Title Symptom assessment of the social and spiritual dimensions in hospice care patients. An exploratory mixed-method study.

Background Hospice care aims to optimise quality of life (QOL) by diminishing physical, psychological, social and spiritual suffering. However, the social and spiritual dimensions are minimally assessed or reported by the multiprofessional team (MT). Therefore, the four dimensional Utrecht Symptom Diary (USD4D) was developed.

Aim To gain insight into the demand, practicality and acceptability of symptom assessment in the social and spiritual dimensions by MTs, using the USD4D for adult patients admitted to Dutch hospice care.

Method This feasibility study with an exploratory mixed-method design was conducted from January to June 2017. Quantitative data were collected from USD4Ds completed by hospice patients, and 30 patient records. Demand was frequency of completed USD4D items and practicality were reports of the social and spiritual dimensions by the MT. Assessment of the social and spiritual dimensions was further explored using focus-group interviews with MTs. Both phases had equal priority and were integrated during data-analysis.

Results The USD4D is completed on average 2.8 times by patients, or once a fortnight. It is a foundation for conversations and in-depth explorations of the spiritual dimension, although some social items of the USD4D could be improved. Integration in daily care depends on competence, interdisciplinary collaboration, and is influenced by gate-keeping.

Conclusion Symptom assessment of the social and spiritual dimension by means of the USD4D has been found to be feasible in terms of demand, practicality, and acceptability. Influencing factors have been identified: professional competence, gate keeping, and interdisciplinary collaboration.

Recommendation Amelioration of assessment of the social dimension is suggested. Competence and interdisciplinary collaboration should be developed to optimise symptom assessment of the social and spiritual dimension.

Keywords hospice care, palliative care, symptom assessment, spirituality, social environment

SAMENVATTING

Titel Symptoomassessment van de sociale en spirituele dimensies in hospice care-patiënten. Een verkennende mixed-method studie.

Achtergrond Hospice care heeft als doel het optimaliseren van kwaliteit van leven door het verminderen van lichamelijk, psychisch, sociaal en spiritueel lijden. Echter, de sociale en spirituele dimensies worden minimaal geadresseerd en gerapporteerd door het

multidisciplinaire team (MT). Het vierdimensionele Utrecht Symptoom Dagboek (USD4D) is daarom ontwikkeld.

Doel Inzicht krijgen in de vraag, bruikbaarheid en aanvaardbaarheid van symptoomassessment van de sociale en spirituele dimensies door het multidisciplinaire team, met behulp van het USD4D bij volwassen Nederlandse hospicepatiënten.

Methode Deze feasibility studie met een verkennend mixed-method design is van januari tot juni 2017 uitgevoerd. Kwantitatieve data zijn verzameld van ingevulde USD4D's en 30 patiëntendossiers. Vraag is onderzocht met de frequentie van ingevulde USD4D's en bruikbaarheid aan de hand van rapportages van het MT. Assessment van de sociale spirituele dimensie is verder verkend met behulp van focusgroep interviews met MT's. Beide fasen hadden gelijke prioriteit en werden tijdens data-analyse geïntegreerd.

Resultaten Patiënten vullen het USD4D 2.8 keer in, oftewel eens per twee weken. Het is een aanleiding voor gesprekken en om dieper in te gaan op de spirituele dimensie. De sociale items van het USD4D kunnen verbeterd worden. Integratie in het zorgproces is afhankelijk van professionele competenties, de mate van interdisciplinair werken van het MT en gate-keeping.

Conclusie Symptoomassessment van de sociale en spirituele dimensie met behulp van de USD4D is haalbaar. Beïnvloedende factoren op het gebruik zijn: professionele competenties, gate-keeping en interdisciplinaire samenwerking.

Aanbevelingen Doorontwikkeling van sociale vragen van het USD4D, concretisering van benodigde competenties en ontwikkeling van interdisciplinaire samenwerking zijn nodig om de implementatie en acceptatie van het USD4D in de dagelijks hospicezorg te optimaliseren.

Keywords hospice care, palliatieve zorg, symptoomassessment, spiritueel, sociaal

INTRODUCTION

Palliative care is defined by the World Health Organization as: *'An approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual'*³. Priority of palliative care is quality of life (QoL) and quality of dying, which entails palliative care having a multidimensional character. This demands knowledge and involvement of a multi-professional team (MT). The MT includes a core team of physicians, nurses, chaplains, and other supporting disciplines. Interdisciplinary collaboration, continuity, and expertise are essential^{4,5}.

When admitted to hospice care, patients suffer from an average of six to seven symptoms concurrently. Four to five of these are clinically relevant, having an intensity score above the cut-off of 3 on a 0-10 point numerical scale⁶. Symptom management is based on palliative reasoning, including assessment, intervention, monitoring, and evaluation of symptoms^{5,7}. Self-assessment is considered to be the 'gold standard'⁸.

Symptom management includes all four dimensions of human existence, meeting psychical, psychological, spiritual, and social needs⁹⁻¹¹. However, the social and spiritual dimensions are minimally assessed or reported in patients' records¹².

Social problems include loss of self-management, dependency, inability to work, being a burden to others, distress of caregivers, and organising home care¹³⁻¹⁶. If not addressed, these problems can increase psychological distress and reduce QoL¹⁵⁻¹⁷.

Spirituality evolves in time and can be triggered by, e.g. pending death^{18,19}. Unmet spiritual needs can affect spiritual well-being and cause spiritual distress, such as hopelessness, a desire for hastened death, and depression^{20,21}. Creating an environment in which spiritual needs can be expressed serves to prevent the development of spiritual distress²².

Tools support the MT to methodically assess social and spiritual problems.¹² The Edmonton Symptom Assessment System (ESAS), a validated clinical tool, is used worldwide²³⁻²⁶ to accurately assess physical and psychological symptoms in palliative-care patients. The ESAS has been translated in Dutch and adapted to the Dutch population, resulting in the Utrecht Symptom Diary (USD)⁸. To optimise QoL, palliative care should focus on all four dimensions. Therefore, the four-dimensional Utrecht Symptom Diary (USD4D) was developed. Using the Ars Moriendi (the art of dying)^{27,28} model, social and spiritual items were added to the USD4D by a team of chaplains and experts in hospice care. Themes that have derived from this model are 1) oneself–the other, 2) doing–undergoing, 3) holding on–

letting go, 4) forgiving–forgetting, and 5) knowing–believing²⁹. The USD4D was digitalised and developed as a computer application, and is used in Dutch hospices.

Feasibility, of the assessment of, the social and spiritual dimensions had not yet been determined in terms of the demand, practicality and acceptability³⁰. Demand describes estimated use; practicality explores the extent to which the USD4D is used; and acceptability focuses on how individuals react to the USD4D³⁰⁻³².

The aim of this feasibility study is to gain insight into the demand, practicality and acceptability of symptom assessment in the social and spiritual dimensions by MTs, using the USD4D for adult patients admitted to Dutch hospice care.

METHOD

Design

This study, with an exploratory mixed-method design, was conducted from January to June 2017. The quantitative phase consisted of two steps to determine: A) demand, using prospectively collected data from USD4Ds completed during hospice admission; and B) practicality, using data derived from patient records³³. To determine acceptability³³, in the qualitative phase, focus-group interviews were conducted with MTs from four hospices. This method triangulation provided a broad perspective on the assessment of the social and spiritual dimensions and compensated for data missing from patient records³⁴. Both phases had equal priority and were integrated during data analysis.

Setting and population

The study was conducted in professional hospices, members of the Dutch Association of Hospice Care. Patients are eligible to be admitted to hospice care when their life expectancy is less than three months. The USD4D is implemented in 17 hospices.

Quantitative phase

In phase 1A, a convenience sample of hospice patients who had been admitted to Dutch hospices and who died in 2016 was used. Patients had to complete at least one USD4D during admission.

For phase 1B, data was collected from patient records of a convenience sample of 10 hospices. Inclusion criteria were: patients ≥ 18 years; admitted to a Dutch hospice for a minimum of 2 weeks and a maximum of 3 months; completed USD4Ds; and deceased in January, June/July or December 2016. This dispersion reduced risk of selection bias, and provided insight into the assessment of the social and spiritual dimensions over the course of one year.

Qualitative phase

A purposive sample of four hospices in which to perform focus-group interviews with MTs was selected based on the frequency of reporting the social and spiritual dimensions. A ranking of hospices was made, and four hospices with high, middle or low outcomes of demand and practicality were invited to participate (Fig.1). This range provided a broad perspective on acceptability and factors influencing assessment of the social and spiritual dimensions. Recommended size for focus groups is six to ten participants³⁵⁻³⁶. For each focus group, three-four nurses, a physician and a chaplain working in the same hospice were invited. Focus-group interviews were performed until data saturation was reached.

Sample size calculation

Recommendations for sample size of a feasibility study range from ten participants per patient group to 50% of the main trial sample³⁷. In current study, based on the number of patients admitted to participating hospices, sample size for phase 1A was estimated at 150 patients.

Phase 1B comprised 10 out of 17 professional hospices using the USD4D. Three patient records per hospice were selected randomly. This sample size of 30 patient records was based on recommendations for feasibility studies³⁷.

Data collection

The main outcomes of this feasibility study were demand, practicality and acceptability of symptom assessment of the social and spiritual dimensions.

Quantitative phase

Demand was defined as frequencies of completed social and spiritual items of the USD4D by hospice patients. The USD4D is a Dutch adapted translation of the ESAS²³⁻²⁶ with an extension of social and spiritual items. The USD core consists of 11 physical and psychological symptoms, and one measure of well-being. Patients can add symptoms and prioritise which symptom requires attention. In daily practice, patients are asked to complete the USD twice a week, or more often if required⁸. The 4D extension comprises six social and spiritual symptoms: value of life, having enough time for myself, carrying what befalls me, letting go of loved ones, balance of life, and being at peace with the ending of life. Because the social and spiritual dimensions fluctuate less, patients are asked to complete the USD4D once a fortnight. The intensity of all symptoms is measured on an 11-point numerical scale. Patients complete the USD4D themselves, with assistance of a professional or loved one if required. All USD4Ds are collected and entered in the USD4D database. The USD4D data was extracted from the database along with patient characteristics, such as gender, age, and primary diagnosis.

Practicality was defined as the extent to which the USD4D is used to support symptom management of the social and spiritual dimensions by the MT. To determine practicality, data including frequency of reports written by the MT and in the multi-professional team meetings (MTMs), were extracted from patient records.

To ensure adequate quality of data, a purpose-developed data extraction tool was used to collect data (Appendix A). Frequencies of reports were categorised using the 4D extension items. Symptom assessment is based on steps of palliative reasoning; therefore, frequencies of assessment, intervention, monitoring, and evaluation were tallied^{5,7}. Furthermore, reports of the USD4D and, where applicable, the reasons patients could not complete the USD4D, were collected.

Qualitative phase

Acceptability was defined as the MT's reflection on the use of the USD4D and was assessed by semi-structured focus-group interviews. In order to initiate discussions, results from the quantitative phase, including a comparison between the overall mean frequencies and the mean frequency for the individual hospice of completed USD4Ds, were presented to participants. An experienced moderator (EdG) guided the interviews, using a semi-structured topic list (Appendix B). The moderator summarised discussions and checked accuracy of summaries for member check. A novice observer (MdL) took notes and observed interactions between participants^{35,36}. All interviews were recorded and transcribed verbatim. Participants' characteristics were gathered using a questionnaire (Appendix C).

Data analysis

Quantitative phase

Quantitative data were analysed using descriptive statistics. Frequencies and means were used to analyse: demand; practicality; and characteristics of patients, hospices and MTs, using SPSS Statistics version 23 (IBM Corporation, Armonk, NY, USA).

Qualitative phase

Analysis of the focus-group interviews was based on conventional content analysis³². Data were explored through open coding. Using axial coding, codes were defined into categories, themes were identified through selective coding. Transcriptions and analysis were checked by a second researcher (SH). Furthermore, critical reflection on personal preconceptions and peer review increased trustworthiness. Constant comparison was used to assess the 'fit' of incoming data with existing categories^{35,36}. An audit trail was logged to provide insight into decisions made. Qualitative data were analysed using NVivo version 11 (QSR international, Victoria, Australia).

Quantitative and qualitative data were integrated during analysis. Results were presented by theme.

Procedures

When admitted to hospice care, patients were invited by hospice staff to participate using their USD4D data for research purposes. Completed USD4Ds were entered in the USD4D database. Data were anonymously exported to a separate dataset for study purposes.

In phase 1B, hospice staffs were invited by email to participate. Participating hospice staffs were able to raise queries by phone and were asked to select three patient records. Data from all records were collected on site by the researcher.

Finally, in phase 2, managers of four hospices were asked to invite members of the MT by email to focus-group interviews. An information letter was included and participants were able to ask questions of the researcher. All focus-group interviews lasted 60-90 minutes and were organised on location to optimise participation.

Ethical issues

This study was conducted according to the principles of the Declaration of Helsinki (October 2013)³⁸ and in accordance with the Medical Research Involving Human Subjects Act (WMO)³⁹ and the Dutch Personal Data Protection Act (Wbp)⁴⁰.

Informed consent to use their data for research purposes was given by patients at admission. Verbal consent was given by participants of the focus-group interviews.

Completed USD4Ds were entered in the USD4D database and anonymously exported to a dataset. In phase 1B, patient records were anonymised on site by hospice staff. Participant characteristics and transcripts of all focus-group interviews were anonymised.

This study was approved by the local Medical Research Ethics Committee (METC) of the University Medical Center Utrecht, protocol number 17-016/C.

RESULTS

Completed USD4Ds from 157 hospice patients were extracted from the USD4D database. Seventy-two (45.9%) of these patients were men. Their mean age was 73, and they were admitted for 35.5 days on average (Table 1). Additionally, 30 patient records were assessed in 10 hospices (Table 2). Eighteen of these patients were men (60%), mean age was 77, and they were admitted for 34.8 days on average (Table 3).

Subsequently, four focus-group interviews were organised with 13 participants (range two-five participants/focus group). In total, seven nurses, three physicians, and three chaplains

participated (Table 4). In two focus groups the entire core MT was present. In other focus groups, a nurse, physician or chaplain was absent due to work-related activities.

Demand

In total, 157 individual patients completed 732 USD4Ds. Social and spiritual items were completed on average 2.8 times per patient, once a fortnight. Information was missing from 13(8.2%) of the patient records. No differences were found in patients' characteristics of patients with or without missing information.

Some hospices altered the frequency of completion of the USD4D; their patients completed the USD4D less frequently than recommended. Main reason was that nurses found it was too great a burden for the patient. In contrast, other hospices decreased time between measurements to once a week. Alterations in frequency were decided by professionals (Table 5).

Practicality and acceptability

In phase 1B, on average, patients completed social and spiritual items 2.2 times, 0.9 times a fortnight. The USD4D was reported three times per patient; 2.6 times (86.7%) by nurses. On average, one out of three patients found completing the USD4D was too daunting.

Few participants experienced the USD4D as yet another tool they had to use, and they described themselves as '*tool tired*' (Table 5). Main reason for use was that it is mandatory for the MTM.

Social dimension

On average, social aspects were reported by nurses 12.5 times per patient per admission. Other professionals reported social items 0.6-1.1 times (Fig.2). Categorised by steps of palliative reasoning, social problems were on average assessed 5.7 times per patient, monitored 6.1 times, and, in contrast, evaluated 0.8 times (Fig.3).

Participants stated they gave much attention to the social dimension, and had many conversations with patients and their loved ones. Practical interventions, e.g. visiting schedules, were communicated verbally. Factors influencing reporting were 1) reporting things twice, 2) forgetting to report, and 3) weighting if information was necessary for other professionals. Some participants stated that conversations with loved ones did not concern their patient and should not be reported in patients' records (Table 5). In contrast, other participants thought reporting was important for other professionals and accountability.

Participants mentioned that the social dimension was insufficiently covered by the USD4D and requested more specific social items.

Spiritual dimension

Spiritual items were mentioned by nurses 11.5 times on average per patient per admission. Other professionals reported spiritual items 1.2 to 2.4 times (Fig.2). Categorised by palliative reasoning, spiritual problems were on average assessed 8.2 times, monitored 5.7 times and evaluated 1.1 times (Fig.3). Participants recognised that evaluation requires more attention and stated that physical items were better evaluated.

Participants thought that the digital USD4D was an improvement on the paper version. It was easier to complete, and an overview of completed USD4Ds provided insight into progression of symptoms. Some nurses stated that most patients could not complete the USD4D themselves, while others stated that only very ill patients or patients who were cognitively impaired could not. This was mostly determined by nurses (Table 5). If a patient was not able to, nurses completed the USD4D. Nurses sat down next to the patient, which enabled the patient to view the USD4D. Moreover, nurses supported the patient in completing the USD4D items, by explaining items and probing.

Participants mentioned that the USD4D supported palliative reasoning: it was described as a practical tool which supports symptom assessment. However, a few participants thought it was better to follow one's intuition than to use a fixed method.

The USD4D was experienced as a starting point for conversations about spiritual issues. Rich conversations emerged and deeper layers of the spiritual dimension were addressed (Table 5). The 4D extension helped give words to spiritual themes. However, participants also stated that the spiritual questions were difficult to ask. Participants experienced some questions as too daunting and stated that patients found the questions difficult to answer (Table 5). In addition, some patients and professionals found it hard to talk about spiritual topics. Professionals mentioned it took competence to use the USD4D and initiate conversations (Table 5). This included asking questions, pausing, and probing. Spiritual items in the USD4D were experienced as being posed negatively. It required a positive approach and skill to stimulate patients' empowerment. If necessary, help was requested from experienced colleagues or chaplains.

Professionals did not always report spiritual items. When reported, delicate issues were often described in global terms to protect patients' privacy. Some participants questioned whether other professionals needed to know everything. Others thought this was important so they could address spiritual issues and tend to patients' needs.

Some participants requested their patients' consent for reporting. For physical and psychological items, consent was not requested. The social and spiritual dimensions are vulnerable topics that were addressed differently. Decisions concerning reporting were often made by professionals. However, some patients did not want issues reported.

Furthermore, all four dimensions were a recurring topic in the MTMs. The USD4D scores were presented in the MTMs, which sometimes provided unexpected insights for other professionals (Table 5). Most participants used MTMs, email or conversations to discuss patients' spiritual needs. Approximately half of the physicians and chaplains read nurses' reports before meeting the patient. Hospices that collaborated interdisciplinary integrated the USD4D and the assessment of the social and spiritual dimensions in daily practice. In contrast, hospices where professionals worked individually, were less able to integrate the USD4D within daily practice.

DISCUSSION

This feasibility study aimed to gain insight into the demand, practicality and acceptability of, symptom assessment in the social and spiritual dimensions by MTs using the USD4D. Demand was identified as the completion by patients of the USD4D as recommended, but was influenced by gate-keeping. Nurses often decided frequency of USD4D assessment, as well as which patients were able to complete the 4D extension. The USD4D is a practical tool to assess social and spiritual symptoms. Competence is required to address social and spiritual issues. The social dimension is insufficiently covered by the USD4D. Some patients and professionals found the spiritual questions difficult. Participants found the USD4D acceptable. The USD4D was a foundation for conversations, and supported an approach to deeper layers of the spiritual dimension.

Patients completed the USD4D on average once a fortnight. This conforms to recommendations for frequency of completing the USD4D. No differences were found between characteristics of patients who completed the USD4D as recommended and patients who did not. This is the first study to investigate the frequency of completing the 4D extension. Further research should be performed to gain insight into the demand of other populations.

Gate-keeping influenced the frequency of completion. Participants mentioned that some patients could not complete the USD4D. This included patients who were too ill or who were cognitively impaired, but was also affected by gate-keeping. Hospices with low frequencies of completed USD4Ds and reports, displayed high levels of gate-keeping. In contrast, hospices that used shared decision-making showed higher frequencies and valued the USD4D better. Supporting our findings, Bausewein et al. (2011)⁴¹ and Daveson et al. (2012)⁴² identified

similar barriers in using patient-reported outcome measuring tools in palliative care. These include lack of training, gate-keeping, and lack of time.

The social and spiritual dimensions are given extensive attention in hospice care; however, they are not always reported. Influencing factors identified were: 1) reporting things twice, 2) forgetting, 3) confidentiality, and 4) not finding it necessary to report. Similarly, De Graaf et al. (2017)¹² found that details would be missed when reporting at the end of a shift, confidentiality was a concern, and some staff found it unnecessary to report. This study was performed in the similar setting, confirming our findings. Using an exploratory mixed-method design, Cheevakasemsook et al. (2006)⁴³ found limited competence, motivation, and confidence were barriers for nursing documentation. Although competence was identified as influencing factor in addressing the social and spiritual items, this reporting barrier was not found in current study.

The USD4D is a foundation for conversations and helps give words to the spiritual dimension. Earlier research by De Graaf et al. (2017)¹² found that nurses experienced 'finding the right words' problematic. In the current study, participants stated that experience and training could prevent this problem. Bausewein et al. (2011)⁴¹ found that the most common factor that influenced the use of tools was provision of information and guidance. Competence and intrinsic motivation are essential for integration of social and spiritual assessment by means of the USD4D in daily care. Recognising its worth and taking time to sit down with a patient increases optimal use of the tool.

The level of interdisciplinary collaboration influenced acceptability of the USD4D by the MT. Hospices with a high level of interdisciplinary collaboration, integrated the USD4D and assessment of the social and spiritual dimensions in daily practice. Hospice where professionals worked individually, experienced more difficulty in integrating the USD4D in daily practice. An interdisciplinary team has been described as: 'an identified collective in which members share common team goals and work interdependently in planning, problem-solving, decision-making, and implementing and evaluating team-related tasks'⁴⁴. Interdisciplinary collaboration can improve patient care and organisational effectiveness⁴⁵. Requesting expert advice from other professionals improves quality of care and increases symptom assessment. Most hospices use the MTM as a means of interdisciplinary collaboration. Some participants highlighted the importance of reporting in order to inform other professionals, and for accountability. This result had also been found by De Graaf et al. (2017)¹², Cheevakasemsook et al. (2006)⁴³, and Björvell et al. (2003)⁴⁶. Interdisciplinary collaboration within an MT benefits from reporting of care^{43,45,46}.

The strengths of this study are the real-life setting and method triangulation by means of the exploratory mixed-method design – it contributes insight into the hospice care provided.

Focus-group interviews provided a broad perspective on the assessment of the social and spiritual dimensions and compensated for missing information. The large number of patients, and completed USD4Ds in the database, give power to quantitative findings. Use of a data-collection tool and an audit trail increased reliability and the possibility of reproducing findings.

However, a limitation of this study is the possibility of selection bias. Patients included in the USD4D database had given informed consent for use of their data in research. Nurses may have influenced inclusion by means of gate-keeping. A convenience sample of three patient records was drawn in each hospice by hospice staff. This increased risk of purposively selecting certain records. However, both samples were similar in terms of patient characteristics, and were a good representation of the population. Furthermore, the number of records assessed fitted the required sample size for a feasibility study^{33,37}. The participants in focus groups may have been purposefully invited by hospice managers. However, the interviews provided rich insights into the assessment of the social and spiritual dimensions by the MT. Participants stated both positive and negative experiences, indicating that socially desirable answers were minimally provided.

Conclusion

Symptom assessment of the social and spiritual dimensions by means of the USD4D has been found to be feasible in terms of demand, practicality, and acceptability. Professional competence, gate-keeping, and interdisciplinary collaboration have been identified as influencing factors. An amelioration of the assessment of the social dimension is suggested and should be further explored in collaboration with experts in the field. Competence of professionals and interdisciplinary collaboration should be further developed to optimise symptom assessment in the social and spiritual dimensions.

REFERENCES

1. Vandembroucke JP, von Elm E, Altman DG, Gøtzsche PC, Mulrow CD, Pocock SJ, Poole C, Schlesselman JJ, Egger M; STROBE Initiative. Strengthening the Reporting of Observational Studies in Epidemiology (STROBE): explanation and elaboration. *Epidemiology*. 2007 Nov;18(6):805-35.
2. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care*. 2007;19(6):349-357.

3. World Health Organization. Palliative care, factsheet N° 402.
<http://www.who.int/mediacentre/factsheets/fs402/en/>. Updated 2015. Accessed November 27, 2016.
4. Spreeuwenberg C, Vissers K, Raats I, van Bommel M, van der Rijt C, Evers P. Zorgmodule palliatieve zorg 1.0. 2013.
5. PAZORI. Algemene principes van palliatieve zorg.
http://www.pallialine.nl/richtlijn/item/index.php?pagina=/richtlijn/item/pagina.php&richtlijn_id=1011. Updated 2016. Accessed November 27, 2016.
6. de Graaf E, Zweers D, de Graeff A, Daggelders D, Teunissen S. Does age influence symptom prevalence and intensity in hospice patients, or not? A retrospective cohort study. *J Geriatrics Palliative Care* 2014;S(1): 7.
7. de Graeff A, Jobse AP, Teunissen SCCM, Verkuijlen MMJD, Vissers KCP, Zylicz Z, Gilsing MG. Algemene principes van palliatieve zorg. *Ned Tijdschr Oncol.* 2017;14:62-5.
8. de Nijs E, Uitdehaag M, Zweers D, et al. In de palliatieve zorg zijn symptomen leidend. *Oncologica* 2011.
9. Saunders C. Hospice. *Mortality.* 1996;1(3):317-321.
10. Saunders C. A personal therapeutic journey. *BMJ.* 1996;313(7072):1599-1601.
11. Saunders C. The last stages of life. *Am J Nurs.* 1965:70-75.
12. de Graaf E, van Klinken M, Zweers D, Teunissen S. From concept to practice, is multidimensional care the leading principle in hospice care, an exploratory mixed method study. *BMJ Supportive & Palliative Care* 2017; 0: 1-9.
13. Radbruch L, Nauck F, Ostgathe C, Elsner F, Bausewein C, Fuchs M, Lindena G, Neuwöhner K, Schulenberg D. What are the problems in palliative care? Results from a representative survey. *Supportive care in cancer.* 2003 Jul 1;11(7):442-51.
14. Bausewein C, Calanzani N, Daveson BA, Simon ST, Ferreira PL, Higginson IJ, Bechinger-English D, Deliens L, Gysels M, Toscani F, Ceulemans L. 'Burden to others' as a public concern in advanced cancer: a comparative survey in seven European countries. *BMC cancer.* 2013 Mar 8;13(1):105.
15. Yokoo M, Akechi T, Takayama T, Karato A, Kikuuchi Y, Okamoto N, Katayama K, Nakanotani T, Ogawa A. Comprehensive Assessment of Cancer Patients' Concerns and the Association with Quality of Life. *Japanese journal of clinical oncology.* 2014 May 14:hyu060.

16. Oechsle K, Wais MC, Vehling S, Bokemeyer C, Mehnert A. Relationship between symptom burden, distress, and sense of dignity in terminally ill cancer patients. *Journal of pain and symptom management*. 2014 Sep 30;48(3):313-21.
17. Nicklasson M, Elfström ML, Olofson J, Bergman B. The impact of individual quality of life assessment on psychosocial attention in patients with chest malignancies: a randomized study. *Supportive Care in Cancer*. 2013 Jan 1;21(1):87-95.
18. Rousseau P. Spirituality and the dying patient. *J Clin Oncol*. 2000;18(9):2000-2002.
19. Vachon M, Fillion L, Achille M. A conceptual analysis of spirituality at the end of life. *J Palliat Med*. 2009;12(1):53-59.
20. Breitbart W, Rosenfeld B, Pessin H, et al. Depression, hopelessness, and desire for hastened death in terminally ill patients with cancer. *JAMA*. 2000;284(22):2907-2911.
21. McClain CS, Rosenfeld B, Breitbart W. Effect of spiritual well-being on end-of-life despair in terminally-ill cancer patients. *Lancet*. 2003;361(9369):1603-1607.
22. Edwards A, Pang N, Shiu V, Chan C. The understanding of spirituality and the potential role of spiritual care in end-of-life and palliative care: A meta-study of qualitative research. *Palliat Med*. 2010;24(8):753-770.
23. Bruera E, Kuehn N, Miller MJ, Selmsler P, Macmillan K. The edmonton symptom assessment system (ESAS): A simple method for the assessment of palliative care patients. *J Palliat Care*. 1991.
24. Chang VT, Hwang SS, Feuerman M. Validation of the edmonton symptom assessment scale. *Cancer*. 2000;88(9):2164-2171.
25. Watanabe SM, Nekolaichuk C, Beaumont C, Johnson L, Myers J, Strasser F. A multicenter study comparing two numerical versions of the edmonton symptom assessment system in palliative care patients. *J Pain Symptom Manage*. 2011;41(2):456-468.
26. Watanabe SM, Nekolaichuk CL, Beaumont C. The edmonton symptom assessment system, a proposed tool for distress screening in cancer patients: Development and refinement. *Psycho-Oncology*. 2012;21(9):977-985.
27. Leget CJW. Van levenskunst tot stervenskunst: Over spiritualiteit in de palliatieve zorg. Lannoo Tielt; 2008.
28. Leget C. Ruimte om te sterven. Lannoo Meulenhoff-Belgium; 2012.

29. van de Geer J, Leget C. How spirituality is integrated system-wide in the Netherlands Palliative Care National Programme. *Progress in palliative Care*. 2012 May 1;20(2):98-105.
30. Bowen DJ, Kreuter M, Spring B, et al. How we design feasibility studies. *Am J Prev Med*. 2009;36(5):452-457.
31. Hagen NA, Biondo PD, Brasher PM, Stiles CR. Formal feasibility studies in palliative care: Why they are important and how to conduct them. *J Pain Symptom Manage*. 2011;42(2):278-289.
32. Polit DF, Beck CT. *Nursing research: Generating and assessing evidence for nursing practice*. Lippincott Williams & Wilkins; 2012.
33. Arain M, Campbell MJ, Cooper CL, Lancaster GA. What is a pilot or feasibility study? A review of current practice and editorial policy. *BMC Med Res Methodol*. 2010;10:67-2288-10-67.
34. Paans W, Sermeus W, Nieweg R, Van Der Schans CP. Prevalence of accurate nursing documentation in patient records. *Journal of advanced nursing*. 2010 Nov 1;66(11):2481-9.
35. Boeije HR. *Analysis in qualitative research*. SAGE; 2010.
36. Holloway I, Wheeler S. *Qualitative research in nursing and healthcare*. John Wiley & Sons; 2010.
37. Cocks K, Torgerson DJ. Sample size calculations for pilot randomized trials: A confidence interval approach. *J Clin Epidemiol*. 2013;66(2):197-201.
38. World Medical Association. World medical association declaration of helsinki: Ethical principles for medical research involving human subjects. *JAMA*. 2013;310(20):2191-2194.
39. MoHWa S. *Wet medisch-wetenschappelijk onderzoek met mensen. Dutch Medical Research Involving Human Subjects Act (WMO). International Publication Series Health, Welfare and Sport. The Hague, 1997;(2): 1–34*. 2015.
40. Persoonsgegevens WB. *Wet van 6 juli 2000, houdende regels inzake de bescherming van persoonsgegevens (wet bescherming persoonsgegevens)*. Staatsblad 2000.
41. Bausewein C, Simon ST, Benalia H, Downing J, Mwangi-Powell FN, Daveson BA, Harding R, Higginson IJ. Implementing patient reported outcome measures (PROMs) in palliative care-users' cry for help. *Health and quality of life outcomes*. 2011 Apr 20;9(1):27.
42. Daveson BA, Simon ST, Benalia H, Downing J, Higginson IJ, Harding R, Bausewein C. Are we heading in the same direction? European and African doctors' and nurses' views and

experiences regarding outcome measurement in palliative care. *Palliative medicine*. 2012 Apr;26(3):242-9.

43. Cheevakasemsook A, Chapman Y, Francis K, Davies C. The study of nursing documentation complexities. *International journal of nursing practice*. 2006 Dec 1;12(6):366-74.

44. Drinka TJ. Interdisciplinary geriatric teams: Approaches to conflict as indicators of potential to model teamwork. *Educational Gerontology: An International Quarterly*. 1994 Jan 1;20(1):87-103.

45. Cherny NI, Fallon M, Kaasa S, Portenoy RK, Currow DC, editors. *Oxford textbook of palliative medicine*. Oxford University Press, USA; 2015 Apr 7.

46. Björvell C, Wredling R, Thorell-Ekstrand I. Prerequisites and consequences of nursing documentation in patient records as perceived by a group of registered nurses. *Journal of clinical nursing*. 2003 Mar 1;12(2):206-14.

TABLES AND FIGURES

Table 1 Patient characteristics USD4D database

		N (%)
Gender	Men	72 (45.9%)
Age	Mean	73.46
	SD	11.74
Primary diagnosis	Cancer	134 (85.4%)
	Organ failure	9 (5.7%)
	Unknown	14 (8.9%)
Religion	Yes	36 (22.9%)
	No	60 (38.2%)
	Unknown	61 (38.9%)

Table 2 Hospice characteristics

Hospice:	1	2	3	4	5	6	7	8	9	10
Beds (N)	10	8	8	10	7	8	5	7	7	6
Nurses RN (N)	18	12	21	15	16	10	17	10	12	12
Nurses other (N)	0	3	0	0	0	0	0	0	5	1
Volunteers (N)	60	80	53	100	45	45	40	30	35	35
Chaplain	Yes	On call	On call	Yes						
Social Worker	On call	On call	On call	Yes	No	No	Yes	On call	Yes	Yes
Psychologist	On call	On call	No	No	No	On call	On call	On call	On call	No

Table 3 Patient characteristics patient records

		N (%)			
Gender	Men	18 (60.0%)			
	Women	12 (40.0%)			
Age	Mean	77.00			
	SD	9.443			
Marital status	Married/living together	13 (43.3%)			
	Widowed	11 (36.7%)			
	Divorced	3 (10.0%)			
	Single	3 (10.0%)			
Living situation	Alone	16 (53.3%)			
	With at least 1 other adult	14 (46.7%)			
Availability informal caregivers	Yes	27 (90.0%)			
Religion	Yes	14 (46.7%)			
	No	13 (43.3%)			
	Missing	3 (10.0%)			
Primary diagnosis	Cancer	28 (93.3%)	Lung	10 (33.3%)	
			Gastrointestinal	8 (26.7%)	
			Prostatic	3 (10.0%)	
			Brain	2 (6.7%)	
			Unknown	2 (6.7%)	
			Breast	1 (3.3%)	
			Hodgkin	1 (3.3%)	
			Ovarian	1 (3.3%)	
		Heart failure	1 (3.3%)		
		Infection	1 (3.3%)		
Karnofsky	30	10 (33.3%)			
	40	7 (23.3%)			
	50	8 (26.7%)			
	70	2 (6.7%)			
	Missing	3 (10.0%)			
Survival time¹	Mean	34.83			
	SD	17.487			

¹ days from admission to death

Table 4 Focus group participants' characteristics

		N (%)
Gender	Female	12 (92.3%)
Age	Mean	50.31
	SD	12.079
Profession	Physician	3 (23.1%)
	Chaplain	3 (23.1%)
	Nurse, RN	6 (46.2%)
	Nurse, RN, MSc	1 (7.7%)
Extra training palliative care	Yes	8 (61.5%)
Years' experience hospice care	Mean	6.94
	SD	4.799

Table 5 Quotes from focus group interviews

Theme	Category	Quote
Demand	Adjusted frequency by hospices	'Experts stated that it is recommended to complete the USD4D once a fortnight. Our hospice decided to fill out the USD4D once a week. Because we have observed the spiritual dimension fluctuating more towards the end of life. So we systematically complete the USD4D once a week.'
Acceptability	Being 'tool-tired' and using ones intuition	'They (<i>nurses</i>) don't feel like an instrument helps. We are getting tired of all those instruments and another tool and this and that. So you think: can I just use my intuition?'
Social dimension	Reporting versus not reporting	'What do I report and what do I not report? In what way is privacy privacy and what does somebody else benefit from knowing.....how much do you benefit yourself from going to a patient blank and just see what happens and not being prejudiced or already having a response?'
Practicality	Patients cannot fill out the USD4D	'Because they (<i>patients</i>) cannot complete the USD4D by themselves. They need to be used to working with an iPad. Nine out of ten patients mostly ask me to complete the USD4D.'
Acceptability	USD4D helps give words to the spiritual dimension	'The USD4D has an additional value to the conversations I have with patients. You get into a deeper layer where you can find out more about someone, if he can open up to you.'
Practicality	Difficult questions	'These are really difficult questions. There are people who don't ask such questions. And then you have to score them. So, you have to explain a lot.'
Practicality	Professional competences	'I think we have very skilled nurses, but in general, competences need to be further developed. What you need for conversations and just being quiet, addressing you own vulnerability or powerlessness, it is all about articulation I think.'
Acceptability	Unexpected findings in the MTM	'When I see the scores in the MTM I find myself looking differently at the patient. It is an eye opener: pay attention to this.'

Figure 1 Total frequencies of social and spiritual reports per hospice

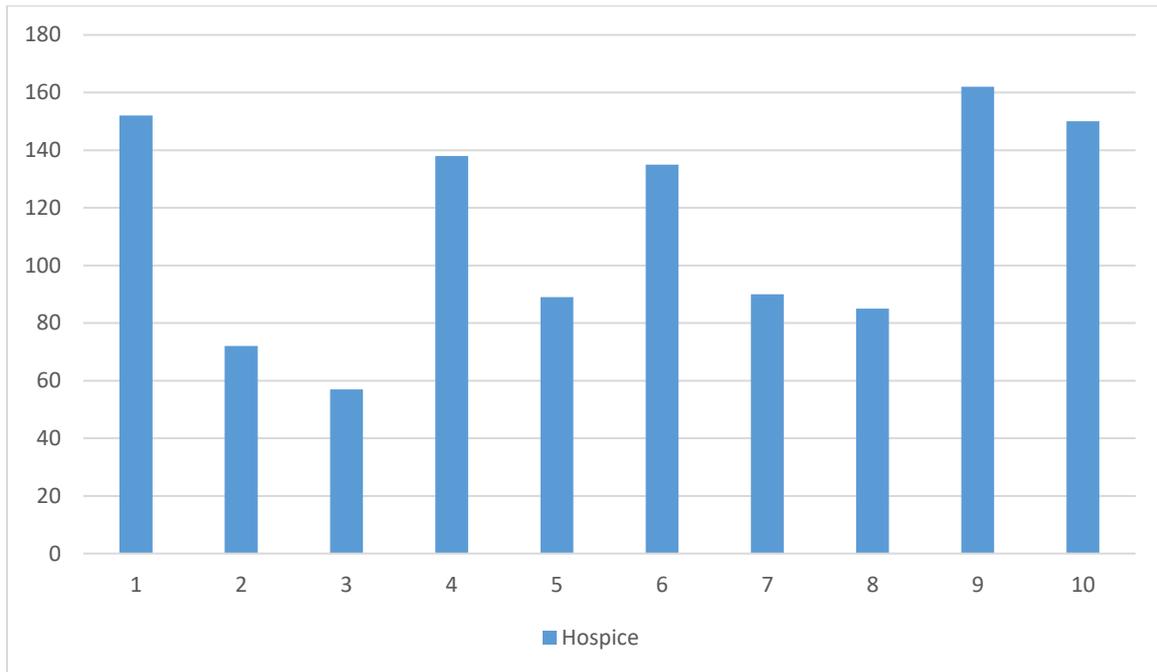


Figure 2 Social and spiritual reports per discipline per patient

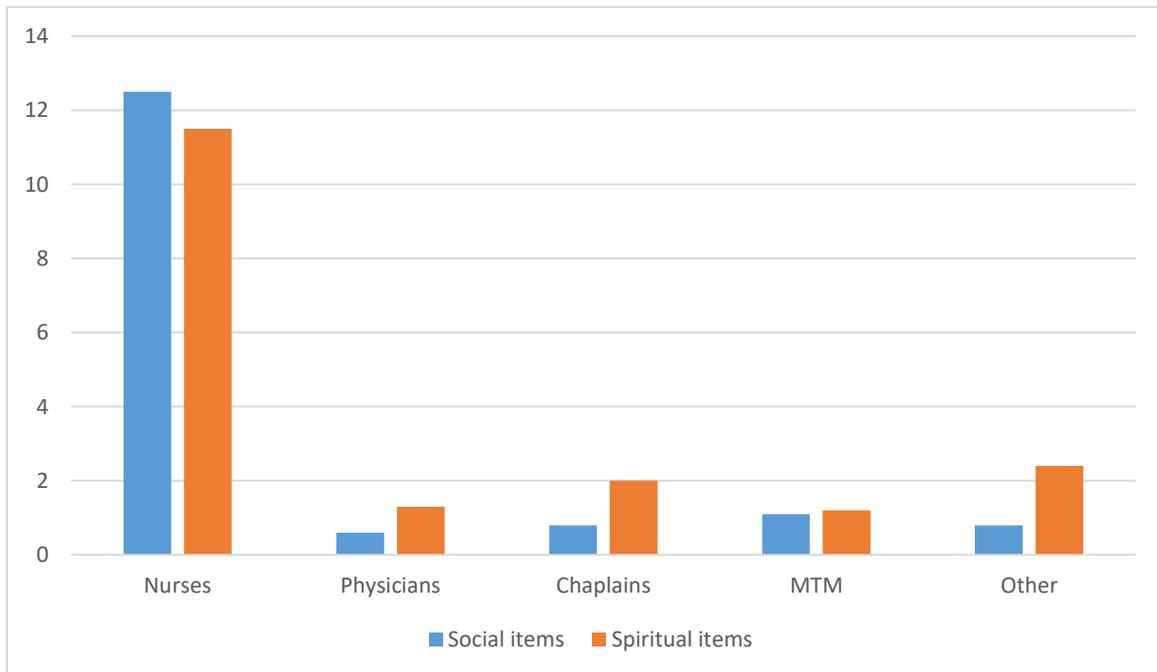
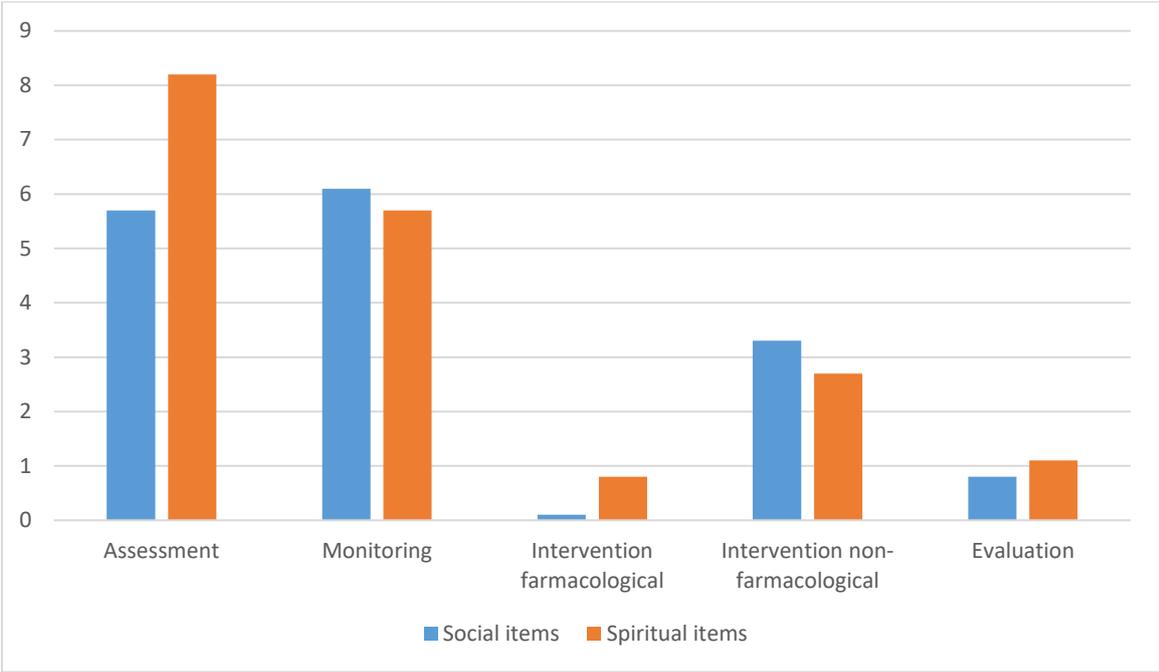


Figure 3 Social and spiritual reports per step palliative reasoning per patient



APPENDICE A: Data extraction tool

Patient records		Soc.				Spir.						Phys.	Psych.	Meas. instr.
		Role patient environment	Presence loved ones/feeling support	Influence illness on loved ones	Sexuality/intimacy	Life has value	Oneself – the other	Doing - undergoing	Holding on – letting go	Forgiving - forgetting	Knowing - believing	Tired	Fear	
Nurse	Ass													
	Monitor													
	Farm. interv													
	Non-farm interv													
	Eval													
Physician	Ass													
	Monitor													
	Farm. interv													
	Non-farm interv													
	Eval													

Chaplain	Ass													
	Monitor													
	Farm interv													
	Non-farm interv													
	Eval													
Social worker	Ass													
	Monitor													
	Farm interv													
	Non-farm interv													
	Eval													
Psychologist	Ass													
	Monitor													
	Farm interv													

	Non-farm interv													
	Eval													
MTM	Ass													
	Monitor													
	Farm interv													
	Non-farm interv Eval													
Other	Ass													
	Monitor													
	Farm interv													
	Non-farm interv Eval													

APPENDIX B: Topic list focus group interviews

What can you tell us about:

- Assessment of the social dimension?
- Monitoring the social dimension?
- Interventions used in the social dimension?
- Evaluation of the social dimension?

- Assessment of the spiritual dimension?
- Monitoring the spiritual dimension?
- Interventions used in the spiritual dimension?
- Evaluation of the spiritual dimension?

- Your experiences with use of the USD4D?

APPENDIX C: Questionnaire characteristics participants focus group interviews



Characteristics participants focus group interviews

What is your age?	
What is your gender?	<input type="checkbox"/> male <input type="checkbox"/> female
What is your profession?	
What is the level of your education?	<input type="checkbox"/> RN <input type="checkbox"/> RN, MSc <input type="checkbox"/> MSc
Have you had any additional training in palliative care? If yes: what?	<input type="checkbox"/> yes: <input type="checkbox"/> no
How long have you been working in hospice care?	