From signal to monitoring:

early detection in palliative nursing care.

An observational quantitative study.

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Introduction

About 54% of all people in the Netherlands die due to the consequences of a non-acute disease.[1,2] These patients are chronically ill for a certain period of time and they will end up in the palliative phase of their disease, where palliative care is needed.[3] The World Health Organisation (WHO) approaches palliative care as focussing on improving the quality of life and prevention and relief of suffering; by means of early identification, assessment, and treatment of physical, psychological, social and existential problems.[4] Palliative care should start as soon as possible to avoid critical care in the last stage of life [5] and can be provided at home, in a hospice or in a hospital. A study showed that 88% of the patients preferred to die at home, 10% in a hospice and 2% in a hospital. This preference should be leading in selecting the place to provide palliative care.[6] Patients admitted to a hospice have a life expectancy of less than three months. In the last weeks of life, patients do experience more problems.[7] Experiencing more problems cause a higher level of distress, associated with impact on quality of life [8] less satisfaction with care [9] and less treatment compliance [10]. Problems should be identified as early as possible in order to provide proper care, and to prevent aggravation and critical care in the last stage of life.[11,12] In The Netherlands specialized nurses in high care hospice practices support patients with complex problems twenty-four hours a day and seven days a week to help the patient deal with these problems.[7,13,14]

Four levels of measuring problems are shown in figure 1. Early identification, monitoring, screening and diagnosing should be applied subsequently in practice to assist the patient and his problems as best as possible. This article will focus on early identification and monitoring.

Different multidimensional (focussing on physical, psychological, social and existential problem areas) assessment tools for early identification and monitoring are available in literature and practice.[15-26] With multidimensionality attention is paid to all problem areas the patient might experience, in congruence with the definition of the WHO.[4]

Tools for early identification are developed for signalling, using dichotomous questions referring to the experience of a symptom or problem. One of these instruments is the Distress Thermometer (DT). Scoring the actual most restrictive problems provides the health care worker the possibility to focus specifically.[27]

Tools for monitoring follow the intensity and changes of a detected symptom over time. With the aid of a Numerical Rating Scale the amount of burden or hinder over time is measured to observe improvement or worsening of the problem.[28] Instruments for monitoring are the Utrecht Symptom Diary (USD) and USD for professionals
(USD-p). The USD is based on the Edmonton Symptom Assessment Scale (ESAS).[28]

Although self-assessment is the most reliable way to measure experienced symptoms, [20,29,30] sometimes the patient is not able. In these cases only the USD-p is used, otherwise both USD and USD-p are used. Concurrently, this study will focus on the DT and USD/USD-p, as these instruments are already used in the hospices of research.
In order to determine whether an intervention should be undertaken in response to a score, representing clinically relevant burden, cut points are used in practice.[31] The cut points for the USD are based on the ESAS, but are not described consistently in literature as each symptom contains a specific score. Generally, a score of four or higher is recommended as cut point.[31,32]

There is insufficient evidence about the use of instruments in practice. Using instruments to identify problems and distress routinely improves the communication with the clinician and patients feel better heard and helped.[33-35] Systematic questioning identifies more symptoms than self-reporting,[34] but physicians identify only a limited number of patients with distress.[36] Nurses, however, are able to identify distress at an early stage, as they are in contact with patients on a daily basis, which leads to building a trustworthy relationship with each patient.[37-39] Nurses should be able to choose and use an appropriate assessment tool, to collect information and monitor problems systematically and methodically over time in order to intervene timely and prevent aggravation.[11,40] To conclude whether nurses are able to use instruments correctly, one must first determine how instruments are used in practice.

Problem statement

In scientific literature and in daily practice, it is not clear whether or in what order early identification and monitoring are carried out in daily practice and in what way nurses, working in high care hospice practices, deal with using measurement instruments.

Aim

The aim of this study is to explore the use of the DT and the consecutive steps (with the USD and USD-p), performed by nurses in high care hospice practices, since these patients have reached the palliative phase and the last complex and critical stage of their disease. With the results, an indication can be provided about the working methods of nurses in the included hospice practices, related to early identification and monitoring of problems. Correct use of the DT and USD/USD-p, and proper implementation improves the quality of palliative care.

Research question

'In what way is the Distress Thermometer used by nurses in daily high care hospice practices and is there a succession with the USD and/or USD-p?'

- Is there a sequence from signal with the DT to monitoring with the USD and/or USD-p, or deploying an intervention?
- In what way are the USD and USD-p used after early identification?

Methods

Design

A quantitative, retrospective, observational and exploratory design was used for this study. Data was collected over time, without burden for vulnerable palliative patients.[41] Since little is known about this topic in literature, the results of this study will be descriptive en explorative.

The Medical Research Ethics Committee (MREC) in Utrecht granted permission to conduct this study.

Setting, population, instruments and sample

Research was done in two high care hospice practices in the Netherlands between January first 2013 and April first 2013. The working methods of nurses, using the DT for early identification and the USD/USD-p for monitoring, were observed through dossier analysis. The primary variable of this study was early identification of problems by nurses with the aid of the DT. This instrument has shown to be reliable and valid in literature, pooled results shows a sensitivity of 0.77 and a specificity of 0.66 in oncological patients.[28,43]

The DT is completed by the patient at admission and consists of five main domains: practical problems, family/social problems, emotional problems, religious/spiritual concerns and physical problems. Different sub-domains can be distinguished.[27]

The secondary variables in this study were the consecutive steps from signal to monitoring after identifying a problem. Consecutive steps is defined as deployment of an intervention and/or monitoring the problem by means of the USD and/or USD-p. The USD is a Dutch version of the ESAS.[28] The validity and reliability of the USD is not described in literature. A patient scores the following items at least twice a week on a eleven-point numerical rating scale (no problem-worst possible): pain, sleeping problems, dry mouth, swallowing problems, loss of appetite, constipation, nausea, shortened of breath, tiredness, anxiety, depressed mood and state of wellbeing. Patient specific problems are scored, and the patient has the possibility to write down which problem should be solved as first. The USD-p is used by health care professionals and shows their interpretation of the problems, experienced by the patient. With aid of the USD-p, the same items as which are used in scoring with the USD are rated, involving the additional items decreased consciousness and confusional state. A five-point numerical rating scale (no complaint-severe, overpowering continuous complaint) is used. The health care professional has the option to write down which symptoms needs to be solved at first.

The USD and USD-p are used concurrently, but if the patient is not able to conduct the USD, only the USD-p is used.

Target was to analyze 37 dossiers: the average stay in a hospice is 30 days [42], fourteen

rooms are available and data was collected over 89 days, resulting in the fact that 41 dossiers could be analyzed. Length of stay is variable and cannot be predicted, so the target was to pursue 90%.

Data collection

Data was collected from dossiers of discharged or deceased patients. A convenience sample with a consecutive selection was used to collect information; all available and suitable dossiers could be analysed in the hospices.[41] All patients gave written informed consent to use their data for research at admission to the hospice. Dossiers from adult patients, admitted ≥ 48 hours were included if the DT was declined or a problem was detected in the anamnesis.

All information in the patient's dossier was written down by nurses. The researcher consulted in what way nurses performed early identification and monitoring in the following parts of the dossiers: anamnesis, reports, care plans, reports of MDC's and the completed DT's, USD's and USD-p's. Once a week, the results of the DT and the USD/USD-p are discussed in a multidisciplinary consultation (MDC), providing the possibility to observe the scores and interventions over time.

Data analysis

Descriptive statistics were used to show percentages on the number of analysed dossiers, the number of nurses working in both hospices and the amount of detected problems. Information from the dossiers was analysed anonymously as no comparison between the hospices would be provided and it was not the purpose of the study to observe individual performance of the nurses.

Data concerning the DT was cross-sectionally analysed. Percentages of detected problems with the DT and anamnesis were shown, after which the monitoring over time was revealed. In addition, consistently using the DT at admission was expressed in a percentage.

Data on the use of the USD and USD-p were cross-sectionally analysed. Percentages on the consistent use (at least twice a week) were calculated. Descriptive statistics were used to analyse use and scores of the USD and USD-p. The mean score for state of wellbeing was calculated, where a comparison was made between the USD and USD-p. This score had to be transposed, as zero means bad if scored with the USD, and good if scored with the USD-p.

Cut points were taken into consideration in showing the deployment of an intervention and/or monitoring the problem over time. A cut point of ≥3 was used for the USD and of ≥1 for the USD-p. Percentages on monitoring over time were also calculated. Based on the listed scores, additional analysis was performed to determine pre-emptive-, cut point-, or crisis interventions, taking the given scores and associated type of interventions into consideration.

Crisis interventions are needed when scores suddenly rise, or remain high over a period. This analysis does not show in what way the nurses actually performed these interventions in practice, as it was not the purpose of this study to show in what way nurses deal with using cut points. Data was analysed with IBM SPSS statistics version 20.0.

Results

Thirty dossiers were analysed. The DT was used in fourteen dossiers (47%), identifying a total of 238 problems (table 1). The anamnesis was used in every dossier, 208 problems were identified. The USD was used in twenty-four (47%) dossiers, identifying 154 problems. The USD-p identified 366 problems and was used in twenty-nine dossiers (94%). Information about the subsequent steps and monitoring over time was most frequently noted down in the nurses' daily reports. The symptoms pain, sleeping problems and tiredness were described most frequently.
A total of twenty-four registered nurses (RN) are working in both hospices.

Consistent use of the DT, USD and USD-p
Reasons for inconsistent use of the DT and USD were tiredness or cognitive impairment of the patient. In two cases, the patient refused to use the instrument (table 2).

Detected problems
With aid of the DT, physical problems were indicated as most restrictive (table 3), especially fatigue (93%), daily activities (79%) and condition/strength (86%). Emotional problems were also frequently mentioned, mostly depression (71%), concentration (50%) and loss of control (50%). Practical problems and religious/spiritual concerns were least mentioned. In the anamnesis, physical and emotional problems were also indicated most frequently. Most restrictive physical problems were fatigue (83%) and pain (63%). Fear was the most restrictive emotional problem (33%). Not all problems that were identified early with the DT were monitored with the USD/USD-p; emotional and physical problems were monitored most frequently.

Interventions and monitoring
Interventions were not always linked to cut points (table 4). Tiredness was scored above the cut point most often (USD 64% and USD-p 61%). Interventions for pain and dry mouth were frequently deployed, even when the score had not reached the cut point. For sleeping problems (74%), swallowing problems (64%), loss of appetite (64%) and constipation (48%), scored with the USD, no intervention was deployed above the cut point. This was almost equal for the USD-p, with the sole difference that 69% of the cases did receive an intervention for constipation.
Problems that were scored with the USD/USD-p were consistently followed in time. The option to score an open symptom was used in 38% percent of the cases. In 20% of the cases, this concerned an emotional symptom, and in 80% of the cases a physical symptom. Nurses scored an open symptom in 29% of all cases, mostly physical problems (74%).
The average score for wellbeing, scored with the USD and scored with the USD-p, differed:

patients mean score was 4,5, and the transposed nurses' mean score was 4,1 (table 5). Figure 2 and 3 shows the distribution between the scores, when classified by score and type of intervention (pre-emptive, reaction to a cut point or crisis intervention) which would be required as a result to a certain score. Patients scored more often above the cut point.

Discussion

The results of this study show that early identification and monitoring of problems is not applied consistently in practice. As the DT was not implemented in both hospices; early identification with the DT was performed in 47% of all cases. For monitoring, the USD-p was most often used (94%). Physical problems were indicated as most restrictive, especially tiredness. Not all domains are monitored with the USD/USD-p, mainly physical and emotional symptoms. Symptoms which are already scored with the USD/USD-p are more consistently monitored over time. Interventions are not consistently deployed as a result of a cut point. In some cases symptoms are scored above the determined cut point after a longer period in which the situation seemed stable, based on the scores.

Early identification

The DT was not implemented in one hospice of research. Practical, family/social and religious/spiritual domains remained more practical and general. Since specific symptoms were not questioned, some problems might remain underexposed. However, these effects have not been studied in practice, as data of both hospices was analysed together. It is clear that early identification needs a low specificity and a high sensitivity; it is better to hear that patients do not need an intervention, than to start an intervention too late.[44] Consistent use of the DT provides the opportunity to identify specific problems at an early stage. Proper implementation is important, providing a starting basis for health care providers.[45,46] Subsequently, symptoms that are identified at an early stage may improve the and quality of care since nurses can perform patient-tailored care in which the patient feels helped and understood.[4,47]

Monitoring

The DT detect problems in all domains. The USD/USD-p mainly focus on physical problems, but also offers the possibility to score other symptoms. This option was used in 29% of all cases. The underlying cause of this low percentage is not known, but it might be due to the complexity of some domains, such as emotional or religious/spiritual symptoms. These subjects are more difficult to discuss in practice, in contrast to physical problems.[28] Monitoring should always be applied multidimensional, distinguishing between the different components since each domain may have the same impact.[28,48] For example, in this study it appears that if end of life is approaching, the patient does experience increased tiredness. Since no distinction is made between physical and mental components, the score seems incorrect, resulting in not deploying a suitable intervention like the fatigue index in practice.[49] Awareness about multidimensionality is important to deploy correct interventions, fitting a

patients need when providing good quality care.[28] Without monitoring, aggravation of a symptom might be detected too late and might worsen, exactly the situation you want to avoid with early identification and monitoring.[28],[12,35] Especially in hospice practices, where nurses are trained to provide complex care for patients with multidimensional problems.[14]

The option when using the USD/USD-p to describe which problem the patient wants to solve first is rarely used in practice. This was also concluded in another study.[48] The current study also shows that the USD-p is used more frequently than the USD, as patients were too tired or had an impaired cognitive status. Here, the scores of nurses must reflect the patient's actual experiences. This study does not reveal an adequate association between nurses an patients scores, but other studies show a poor association. It is not clear where these differences are based on.[51-53] In practice, nurses should learn to score adequately the actual experiences of the patient and stay alert in monitoring and in identifying new emerging problems. Listening to patients and talking to them on a daily basis, provides insight in the preferences of the patients to solve problems, making the nurse increasingly capable to actually reflect the patient's experiences and preferences.[33,35,54] Good communication skills are important to achieve interaction, in order to provide good quality care.[28,55]

Interventions

This study shows that there was no uniform working method among nurses for deploying interventions in reaction to cut points. Scores suddenly raised, or remained high over a period of time. In some cases, pre-emptive interventions were immediately deployed since it was expected that scores would rise. However, responding to a symptom should consist of good assessment techniques, preventive regimes and frequent monitoring.[56] It is not clear whether cut points are actually known in practice. Proper education about dealing with cut points is necessary. If a deployed intervention does not result in lower scores, an adaption of the intervention is required to avoid worsening.[56]

Early identification, monitoring and deploying interventions to carefully and realistically approach symptoms may contribute to improvement of quality of life and quality of care.[5] Quality of life is different for each domain and each patient, and depends partly of experienced expectations.[55][57]

Limitations

This study contains limitations. First, only written data from the dossiers was analyzed by just one researcher. This might affect the reliability, although most of the studied data consisted of the follow up of already listed data.

Additionally, the DT was not implemented in both hospices during this research, resulting in

less available data, possibly causing the occurrence of bias.[41] The USD –p was more often used than the USD. Less problems are indicated and taken into account, possibly affecting the reliability.[41]

More insight in the working methods of nurses could have been obtained, if this study had included examining the kind of interventions that were deployed in response to scores. This would clarify whether appropriate interventions were deployed, their necessity, and actual use of crisis interventions.

Finally, nurses opinion about the use of the instruments and the interpretation of scores should have been requested, in order to obtain an overall view about use in daily nursing hospice practice.

Conclusion

This descriptive study provides the first insights into the use of the DT, USD and USD-p in hospice practices. None of the instruments is used consistently in practice. Interventions as a response to cut points are not consequently performed. This may lead to worsening of the symptom score. Communication, education, proper implementation and a uniform working method could contribute to improved use of early identification and monitoring.

The DT should be properly implemented and consistently used in practice to multidimensional identify problems. Scoring patient specific problems with the USD/USD-p prevents paying attention to only one specific domain. Nurses should use an uniform working method in dealing with cut points and deploying interventions. Problems must be discussed daily, to determine to what extent the patient needs an intervention. Multidimensionality in symptoms must be distinguished in scoring and evaluating.

Further research should be conducted to reveal a comparison between hospices where the DT is, and where it is not implemented, to observe its effects in practice. Knowledge about to what extent nurses in hospice practices are able to discuss problems on all domains could provide a basis for further education. More insight must be obtained about the extent to which nurses are able to score representatively, reflecting the experiences of the patient. The actual level of nurses' knowledge to deal with cut points must be known to improve quality of care. Last, further research is needed to determine which interventions are deployed after early identification and monitoring, and whether these interventions are appropriate and fit the needs of patients.

Reference list

(1) Velden van der LFJ, Francke AL, Hingstam L, Willems DL. Sterfte aan kanker en andere chronische aandoeningen, kenmerken in 2006 en trends vanaf 1996. 2007; Available at: http://www.nivel.nl/sites/default/files/bestanden/Sterfte-aan-kanker-en-andere-chronische-aandoeningen.pdf. Accessed 05/15, 2013.

(2) CBS Statline. Sterfte; kerncijfers naar diverse kenmerken. 2012; Available at: http://statline.cbs.nl/StatWeb/publication/?DM=SLNL&PA=37979NED&D1=0&D2=a&HDR=T&STB=G1&VW=T. Accessed 05/15, 2013.

(3) NIVEL, van der Velden L. et al. Nederlands Instituut voor onderzoek van de gezondheidszorg, dossier palliatieve zorg. 2012; Available at: http://www.nivel.nl/dossier/hoeveel-mensen-hebben-behoefte-aan-palliatieve-zorg. Accessed 05/15, 2013.

(4) World Health Organization. WHO definition of palliative care. 2002; Available at: http://www.who.int/cancer/palliative/definition/en/. Accessed 05/15, 2013.

(5) Ministerie van VWS. Plan van aanpak palliatieve zorg (2008-2010).2008. Available at: http://www.rijksoverheid.nl/documenten-en-publicaties/kamerstukken/2008/04/15/plan-van-aanpak-palliatieve-zorg-2008-2010%5B2%5D.html. Accessed 05/02, 2013.

(6) Abarshi E, Onwuteaka-Philipsen B, Donker G, Echteld M, Van den Block L, Deliens L. General practitioner awareness of preferred place of death and correlates of dying in a preferred place: a nationwide mortality follow-back study in the Netherlands. J Pain Symptom Manage 2009 Oct;38(4):568-577.

(7) Graaf d, E., Vrehen HM, Gamel C, Teunissen SCCM. Ziekenhuisopnames van oncologische patiënten in de palliatieve fase, een systematisch literatuurreview. Nederlands Tijdschrift voor Palliatieve zorg 2009;10(3):6-16.

(8) Skarstein J, Aass N, Fossa SD, Skovlund E, Dahl AA. Anxiety and depression in cancer patients: relation between the Hospital Anxiety and Depression Scale and the European Organization for Research and Treatment of Cancer Core Quality of Life Questionnaire. J Psychosom Res 2000 Jul;49(1):27-34.

(9) Von Essen L, Larsson G, Oberg K, Sjoden PO. 'Satisfaction with care': associations with health-related quality of life and psychosocial function among Swedish patients with endocrine gastrointestinal tumours. Eur J Cancer Care (Engl) 2002 Jun;11(2):91-99.

(10) Jacobsen PB. Screening for psychological distress in cancer patients: challenges and opportunities. J Clin Oncol 2007 Oct 10;25(29):4526-4527.

(11) Snowden A, White CA, Christie Z, Murray E, McGowan C, Scott R. The clinical utility of the distress thermometer: a review. Br J Nurs 2011 Feb 24-Mar 9;20(4):220-227.

(12) Korte d, M.C., Teunissen SCCM. Beter thuis sterven? Vroegsignalering door de thuiszorg bij patiënten in de palliatieve fase. Netwerk Palliatieve Zorg voor Terminale Patiënten Nederland (NPTN) 2009 03.

(13) Associatie High Care Hospices. Keurmerk Palliatieve Zorg voor Hospices en Units Palliatieve zorg bij verpleeghuizen.2013; Available at: http://www.hospices-highcare.nl/Home.aspx. Accessed 05/15, 2013.

(14) Academisch Hospice Demeter. Organisatie, visie. 2012; Available at: http://www.hospicedemeter.nl/organisatie.html. Accessed 05/15, 2013.

(15) Richards CT, Gisondi MA, Chang CH, Courtney DM, Engel KG, Emanuel L, et al. Palliative care symptom assessment for patients with cancer in the emergency department: validation of the Screen for Palliative and End-of-life care needs in the Emergency Department instrument. J Palliat Med 2011 Jun;14(6):757-764.

(16) Stiel S, Pollok A, Elsner F, Lindena G, Ostgathe C, Nauck F, et al. Validation of the symptom and problem checklist of the German Hospice and Palliative Care Evaluation (HOPE). J Pain Symptom Manage 2012 /;43(3):593-605.

(17) Shim EJ, Lee KS, Park JH, Park JH. Comprehensive needs assessment tool in cancer (CNAT): the development and validation. Support Care Cancer 2011 Dec;19(12):1957-1968.

(18) Annells M, Koch T. 'The real stuff': implications for nursing of assessing and measuring a terminally ill person's quality of life. J Clin Nurs 2001 Nov;10(6):806-812.

(19) Aoun SM, Monterosso L, Kristjanson LJ, McConigley R. Measuring symptom distress in palliative care: Psychometric properties of the Symptom Assessment Scale (SAS). J Palliat Med 2011 Mar;14(3):315-321.

(20) Osse BH, Vernooij-Dassen MJ, Schade E, Grol RP. A practical instrument to explore patients' needs in palliative care: the Problems and Needs in Palliative Care questionnaire short version. Palliat Med 2007 Jul;21(5):391-399.

(21) Hardy JR, Edmonds P, Turner R, Rees E, A'Hern R. The use of the Rotterdam Symptom Checklist in palliative care. J Pain Symptom Manage 1999 Aug;18(2):79-84.

(22) Boudreaux ED, O'Hea EL, Grissom G, Lord S, Houseman J, Grana G. Initial development of the Mental Health Assessment and Dynamic Referral for Oncology (MHADRO). J Psychosoc Oncol 2011 Jan;29(1):83-102.

(23) Frost GW, Zevon MA, Gruber M, Scrivani RA. Use of distress thermometers in an outpatient oncology setting. Health Soc Work 2011 Nov;36(4):293-297.

(24) Pigott C, Pollard A, Thomson K, Aranda S. Unmet needs in cancer patients: development of a supportive needs screening tool (SNST). Support Care Cancer 2009 Jan;17(1):33-45.

(25) Knight L, Mussell M, Brandl T, Herschbach P, MartenMittag B, Treiber M, et al. Development and psychometric evaluation of the basic documentation for psycho-oncology, a tool for standardized assessment of cancer patients. J Psychosom Res 2008 Apr;64(4):373-381.

(26) Dudgeon DJ, Knott C, Chapman C, Coulson K, Jeffery E, Preston S, et al. Development, Implementation, and Process Evaluation of a Regional Palliative Care Quality Improvement Project. J Pain Symptom Manage 2009 /;38(4):483-495.

(27) Integraal Kankercentrum Zuid. Lastmeter. 2012; Available at: http://www.ikz.nl/page.php?id=3178&nav_id=299. Accessed 2/21, 2013.

(28) Zylicz Z, Teunissen SCCM, de Graeff A. Inleiding in palliatieve zorg > algemene inleiding richtlijnen palliatie. 2010; Available at: http://www.pallialine.nl/inleiding. Accessed 02/23, 2012.

(29) Chochinov HM, Hassard T, McClement S, Hack T, Kristjanson LJ, Harlos M, et al. The patient dignity inventory: a novel way of measuring dignity-related distress in palliative care. J Pain Symptom Manage 2008 Dec;36(6):559-571.

(30) Stiel S, Matthes ME, Bertram L, Ostgathe C, Elsner F, Radbruch L. Validation of the new version of the minimal documentation system (MIDOS) for patients in palliative care : the German version of the edmonton symptom assessment scale (ESAS). Schmerz 2010 Dec;24(6):596-604.

(31) Oldenmenger WH, de Raaf PJ, de Klerk C, van der Rijt CC. Cut Points on 0-10 Numeric Rating Scales for Symptoms Included in the Edmonton Symptom Assessment Scale in Cancer Patients: A Systematic Review. J Pain Symptom Manage 2012 Sep 24.

(32) Selby D, Cascella A, Gardiner K, Do R, Moravan V, Myers J, et al. A single set of numerical cutpoints to define moderate and severe symptoms for the Edmonton Symptom Assessment System. J Pain Symptom Manage 2010 Feb;39(2):241-249.

(33) Carlson LE, Waller A, Mitchell AJ. Screening for distress and unmet needs in patients with cancer: review and recommendations. J Clin Oncol 2012 Apr 10;30(11):1160-1177.

(34) White C, McMullan D, Doyle J. "Now that you mention it, doctor ... ": symptom reporting and the need for systematic questioning in a specialist palliative care unit. J Palliat Med 2009 May;12(5):447-450.

(35) Snowden A, White CA, Christie Z, Murray E, McGowan C, Scott R. Helping the clinician help me: towards listening in cancer care. Br J Nurs 2012 May 24-Jun 13;21(10):S18, S20-6.

(36) Fallowfield L, Ratcliffe D, Jenkins V, Saul J. Psychiatric morbidity and its recognition by doctors in patients with cancer. Br J Cancer 2001 Apr 20;84(8):1011-1015.

(37) Granda-Cameron, C., Viola, S.R., Lynch, M.P., Polomano, R.C. Measuring Patient-Oriented outcomes in Palliative care: functionality and quality of life. 2008;12(1):65-77.

(38) Hagelin CL, Wengstrom Y, Tishelman C, Furst CJ. Nurses' experiences of clinical use of a quality of life instrument in palliative care. Contemp Nurse 2007 Dec;27(1):29-38.

(39) Vallerand AH, Musto S, Polomano RC. Nursing's role in cancer pain management. Curr Pain Headache Rep 2011 Aug;15(4):250-262.

(40) Thewes B, Butow P, Stuart-Harris R, Greater Southern Area Health Service Screening Collaborative Group. Does routine psychological screening of newly diagnosed rural cancer patients lead to better patient outcomes? Results of a pilot study. Aust J Rural Health 2009 Dec;17(6):298-304.

(41) Portney LG, Watkins MP. Exploratory research: observational designs. Foundations of clinical research, applications to practice. Third edition ed. New Jersey: Pearson Education International; 2009. p. 277-299.

(42) Hochstenbach L, Reitsma N., Groot M, Janssen W, Galesloot C. Registratie palliatieve zorg in hospicevoorzieningen, REPAL jaarrapportage 2010. 2011; Available at: http://www.iknl.nl/uploaded/docs/Landelijk/palliatieve%20zorg/REPAL/REPAL%20jaarrapportage%202010.pdf. Accessed 10/02, 2012.

(43) Mitchell AJ. Pooled results from 38 analyses of the accuracy of distress thermometer and other ultra-short methods of detecting cancer-related mood disorders. J Clin Oncol 2007 Oct 10;25(29):4670-4681.

(44) Payne A, Barry S, Creedon B, Stone C, Sweeney C, O'Brien T, et al. Sensitivity and specificity of a two-question screening tool for depression in a specialist palliative care unit. Palliat Med 2007 Apr;21(3):193-198.

(45) Linge v, R. Innoveren in de gezondheidszorg. Theorie, praktijk en onderzoek. First edition ed. Maarssen: Elsevier Gezondheidszorg; 2006.

(46) Straus S, Tetroe J, Graham ID. Appropriation of the value of the communicated knowledge through implementation or commercialization. Knowledge translation in healtcare, moving from evidence to practice. First edition ed. UK: BMJ books, Wiley-Blackwell, a John Wiley & Sons, Ltd., publication; 2009. p. 284-285.

(47) Vissers KC, van den Brand MW, Jacobs J, Groot M, Veldhoven C, Verhagen C, et al. Palliative Medicine Update: A Multidisciplinary Approach. Pain Pract 2012 Dec 14.

(48) Shah M, Quill T, Norton S, Sada Y, Buckley M, Fridd C. "What bothers you the most?" Initial responses from patients receiving palliative care consultation. Am J Hosp Palliat Care 2008 Apr-May;25(2):88-92.

(49) de Raaf PJ, de Klerk C, Timman R, Busschbach JJ, Oldenmenger WH, van der Rijt CC. Systematic monitoring and treatment of physical symptoms to alleviate fatigue in patients with advanced cancer: a randomized controlled trial. J Clin Oncol 2013 Feb 20;31(6):716-723.

(50) Radbruch L, Sabatowski R, Loick G, Jonen-Thielemann I, Kasper M, Gondek B, et al. Cognitive impairment and its influence on pain and symptom assessment in a palliative care unit: development of a Minimal Documentation System. Palliat Med 2000 Jul;14(4):266-276.

(51) Rhondali W, Hui D, Kim SH, Kilgore K, Kang JH, Nguyen L, et al. Association between patient-reported symptoms and nurses' clinical impressions in cancer patients admitted to an acute palliative care unit. J Palliat Med 2012 Mar;15(3):301-307.

(52) Nakaguchi T, Okuyama T, Uchida M, Ito Y, Komatsu H, Wada M, et al. Oncology nurses' recognition of supportive care needs and symptoms of their patients undergoing chemotherapy. Jpn J Clin Oncol 2013 Apr;43(4):369-376.

(53) Horton R. Differences in assessment of symptoms and quality of life between patients with advanced cancer and their specialist palliative care nurses in a home care setting. Palliat Med 2002 Nov;16(6):488-494.

(54) Sowden AJ, Forbes C, Entwistle V, Watt I. Informing, communicating and sharing decisions with people who have cancer. Qual Health Care 2001 Sep;10(3):193-196.

(55) EAPC. White Paper for Standards and Norms for Hospice and Palliative Care in Europe. 2011; Available at: http://www.eapcnet.eu?Themes/Organisation/EAPCstandardsNorms.aspx. Accessed 06/26, 2013.

(56) Librach SL, Bouvette M, De Angelis C, Farley J, Oneschuk D, Pereira JL, et al. Consensus recommendations for the management of constipation in patients with advanced, progressive illness. J Pain Symptom Manage 2010 Nov;40(5):761-773.

(57) Pastrana T, Junger S, Ostgathe C, Elsner F, Radbruch L. A matter of definition--key elements identified in a discourse analysis of definitions of palliative care. Palliat Med 2008 Apr;22(3):222-232.

Tabels and figures

Figure 1: levels of measuring problems

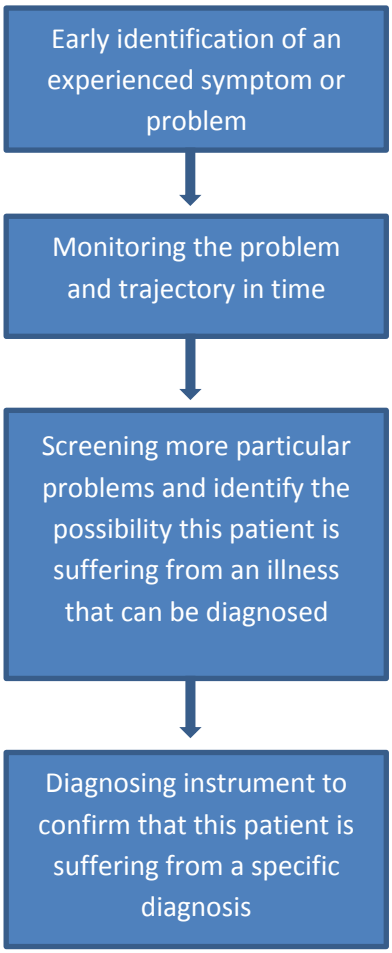


Table 1: Basic information

Instrument Domain Location	N instrument used	N identified problems	N domain identified problems DT	N domain identified problems anamnesis	N location listed problems												
					Pain	Sleeping problem	Dry mouth	Swallowing problems	Appetite	Consti-pation	Decreased consciousness	Nausea	Shortened of breath	Tired-ness	Anxiety	Depressed mood	Confusional state
DT	14	240															
Anamnesis	30	208															
USD	24	154															
USD-p	29	366															
Practical			14	3													
Family/ social			3	11													
Emotional			53	36													
Religious/ spiritual			5	4													
Physical			158	153													
Other			7	1													
Anamnesis					298	238	186	34	153	199	49	61	211	342	71	94	75
Daily care plan					223	12	61	4	53	92	8	25	83	131	43	42	61
MDC					209	12	61	4	28	84	8	21	74	126	43	43	57
Other place					22	3	0	0	0	7	0	3	1	1	2	0	13

Table 2: consistent use of DT, USD, USD-p (N=30)

Instrument (N=30)	n yes	Percentage
Distress Thermometer (DT)	14	47
Utrecht Symptom Diary (USD)	14	47
Utrecht Symptom Diary for health care providers (USD-p)	28	94
Reasons for no consistent use DT (N=16)		
Refused by patient	2	13
Not used in practice yet	9	56
Not described	5	31
Reason for no consistent use USD (N=6)		
Patient to tired	2	33
Cognitive impairment	1	17
Not described	3	50
Reason for no consistent use USD-p (N=1)		
Too short stay in hospice	1	100

Table 3: Early identification with DT and anamnesis, and monitored problems.

Distress Thermometer N=14				Anamnesis N=30			Monitored USD/USD-p N=30	
Domain DT	**Specific problem**	**N**	**% yes**	**Problem anamnesis**	**N**	**% yes**	**Yes/No**	**%yes**
Practical Problems	Child Care	3	21	Child care	1	3	No	
	Transportation	3	21	Transportation	1	3	No	
	Financial	3	21	Financial	1	3	No	
	Housing	2	14				No	
	Housekeeping	2	14				No	
	Work/school/ study	0	0				No	
	Insurance	1	7				No	
Family / Social Problems	Dealing with partner	1	7				No	
	Dealing with children	1	7				No	
	Dealing with friends/family	1	7				No	
				Carrying capacity family	4	14	No	
				Social network	2	7	No	
				Unburden care giver at home	5	17	No	
Emotional Problems	Keeping emotions under control	6	43	Emotional problems	1	3	Yes	7
	Depression	10	71	Depression	7	23	Yes	100
	Loneliness	3	21	Loneliness	2	7	No	
	Fears	5	36	Fears	10	33	Yes	100
	Memory	5	36				No	
	Self confidence	4	29				Yes	3
	Tension/ nervousness	5	36				No	
	Concentration	7	50				Yes	100
	Feelings of guilt	1	7				No	
	Loss of control	7	50				No	
	Dependence on others	0	0				No	
				Confusion	7	23	Yes	100
				Impotence	5	17	Yes	3

				Uncertainty	3	10	Yes	3
				Anger	1	3	No	
Religious/ spiritual Concerns	Meaning of life	3	21	Spiritual basis	1	3	No	
	Trust in God/religion	2	14	Trust in God/religion	3	10	No	
Physical Problems	Constipation	4	29	Constipation	11	37	Yes	100
	Eating	9	64	Eating	13	43	Yes	100
	Mouth sores	8	57	Mouth sores	3	10	No	
	Nausea	8	57	Nausea	12	40	Yes	100
	Pain	8	57	Pain	19	63	Yes	100
	Skin dry/itchy	5	36	Skin dry/itchy	1	3	No	
	Shortness of breath/ breathing	7	50	Shortness of breath/ breathing	16	53	Yes	100
	Weight change	7	50	Weight change	2	7	No	
	Fatigue	13	93	Fatigue	25	83	No	
	Appearance	4	29				No	
	Changes in urination	7	50				Yes	3
	Diarrhea	1	7				No	
	Feeling swollen	4	29				No	
	Fever	2	14				No	
	Nose dry/ congested	6	43				Yes	3
	Sexual	0	0				No	
	Sleep	7	50				Yes	100
	Speech/talking	5	36				No	
	Taste	5	36					
	Tingling in hand/feet	3	21				Yes	3
	Bathing/ dressing	10	71				No	
	Daily activities	11	79				No	
	Out of shape/ condition	12	86				Yes	100
	Muscle strength	12	86				Yes	3

				Problems with bowel movements	3	10	No	
				Incontinent	2	7	Yes	3
				Fluid accumulation	2	7	Yes	7
				Chewing problems	2	7	No	
				Dry mouth	12	40	Yes	100
				Dysphagia	5	17	No	
				Skin problems	1	3	Yes	3
				Touch- and taste problems	2	7	Yes	7
				Mucus	1	3	Yes	3
				Sticky mucus	1	3	Yes	3
				Sleeping problems	14	47	No	
				Perspire	2	7	No	
				Assistance with daily activities	1	3	No	
				Impaired hearing and eyesight	2	7	No	
				Orientation problems	1	3	No	
Other Problems	Open area	7	50	Specific problem	1	3	Yes	100

Table 4: Specific problems, scored with the USD and USD-p and responses to interventions.

	Utrecht Symptom Diary (USD) (N patients=24, N scores=154)								Utrecht Symptom Diary for health care providers (USD-p) (N patients=29, N scores= 366)							
Symptom	**Score ≤3 N (%)**	**Intervention N**		**Score >3 N (%)**	**Intervention N**		**Missing N (%)**	**Symptom monitored in time (%)**	**Score ≤1 (%)**	**Intervention N**		**Score >1 (%)**	**Intervention N**		**Missing N (%)**	**Symptom monitored in time (%)**
		Yes (%)	**No (%)**		**Yes**	**No**				**Yes**	**No**		**Yes**	**No**		
Pain	95 (62)	77 (81)	18 (19)	47 (31)	45 (96)	2 (4)	12 (8)	92	271 (74)	227 (84)	44 (16)	87 (24)	83 (95)	4 (5)	8 (2)	97
Sleeping problems	107 (70)	12 (11)	95 (89)	19 (12)	5 (26)	14 (74)	28 (18)	89	323 (89)	55 (17)	268 (83)	32 (9)	10 (31)	22 (69)	11 (3)	96
Dry mouth	58 (38)	40 (69)	18 (31)	71 (46)	55 (77)	16 (23)	25 (16)	89	223 (61)	124 (56)	99 (44)	137 (38)	113 (82)	24 (18)	6 (2)	95
Swallowing problems	114 (74)	2 (2)	112 (98)	14 (9)	5 (36)	9 (64)	26 (17)	86	328 (90)	23 (7)	305 (93)	29 (8)	6 (21)	23 (79)	9 (3)	95
Loss of appetite	75 (49)	9 (12)	66 (88)	40 (26)	12 (30)	28 (70)	39 (25)	85	239 (65)	24 (10)	215 (90)	102 (28)	33 (32)	69 (68)	25 (7)	95
Constipation	88 (57)	33 (38)	55 (62)	29 (19)	15 (52)	14 (48)	37 (24)	86	301 (83)	114 (38)	187 (62)	36 (10)	25 (69)	11 (31)	29 (8)	95
Decreased consciousness									336 (92)	0 (0)	336 (100)	22 (6)	1 (5)	21 (95)	8 (2)	96
Nausea	119 (77)	26 (22)	93 (78)	8 (5)	7 (88)	1 (22)	27 (18)	86	338 (92)	53 (16)	285 (84)	22 (6)	18 (82)	4 (18)	6 (2)	95
Shortened of breath	87 (57)	41 (47)	46 (53)	40 (26)	30 (75)	10 (25)	27 (18)	88	298 (81)	148 (50)	150 (50)	60 (16)	50 (83)	10 (17)	8 (2)	96
Tiredness	26 (17)	19 (73)	7 (27)	99 (64)	73 (74)	26 (26)	29 (19)	90	108 (30)	67 (62)	41 (38)	252 (69)	154 (61)	98 (39)	6 (2)	96
Anxiety	110 (71)	6 (5)	104 (95)	16 (10)	13 (68)	3 (32)	28 (18)	88	329 (90)	61 (19)	268 (81)	22 (6)	13 (59)	9 (41)	15 (4)	96
Depressed mood	107 (70)	3 (3)	104 (97)	18 (12)	2 (89)	16 (11)	29 (18)	84	329 (90)	22 (7)	307 (93)	31 (9)	7 (23)	24 (77)	6 (2)	95
Confusional state									332 (91)	44 (13)	288 (87)	26 (7)	22 (85)	4 (15)	8 (2)	96
Open symptom (USD N=106), USD-p N=59)	24 (23)	15 (63)	9 (37)	27 (26)	23 (85)	4 (15)	55 (52)	73	13 (22)	7 (54)	6 (46)	25 (42)	23 (92)	2 (8)	21 (36)	67

Table 5: wellbeing

Instrument	N	Mean	Std. deviation	Median
USD	111	4,5	1,8	5,0
USD-p	348	4,1	1,2	6,0

Figure 2: graphical display distribution scores, USD

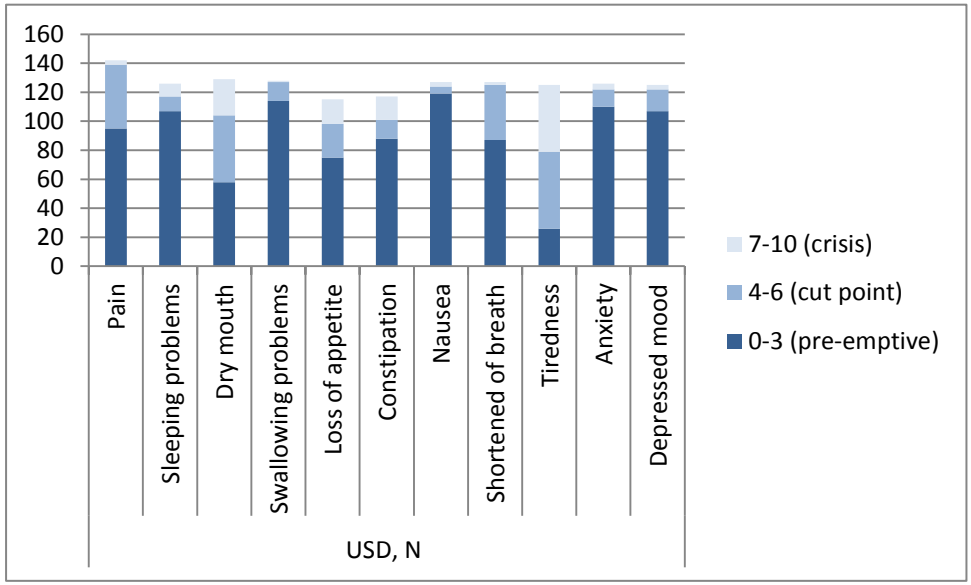
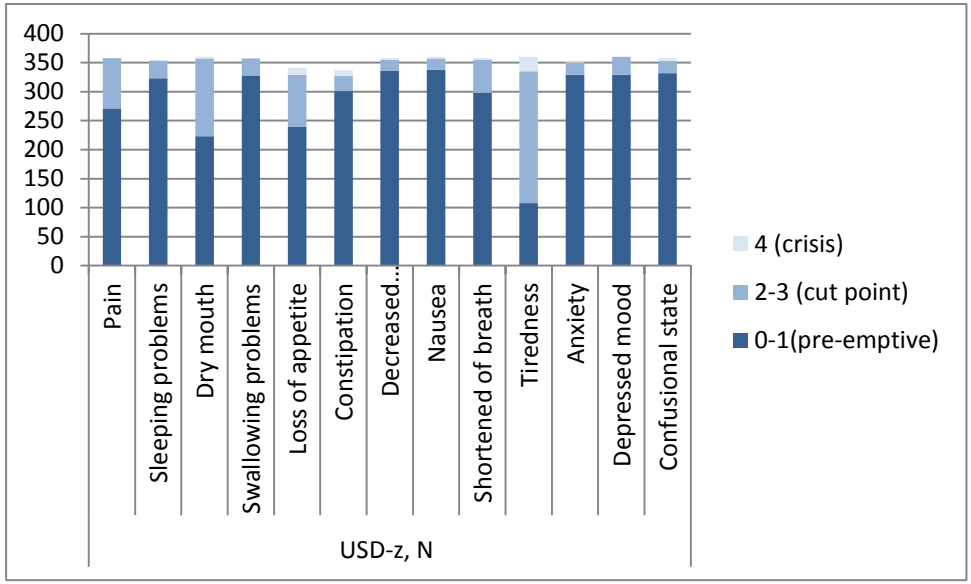


Figure 3: graphical display distribution scores, USD-p



Dutch Summary

From signal to monitoring: early detection in palliative nursing care. A quantitative observational study.

Inleiding

Patiënten in de palliatieve fase van hun ziekte kunnen problemen binnen verschillende domeinen ervaren. Symptomen moeten multidimensioneel benaderd, vroegtijdig gesignaleerd, en gemonitord worden om verergering te voorkomen. Meetinstrumenten zijn een belangrijk hulpmiddel voor vroegsignalering en monitoren. Het is niet duidelijk op welke manier verpleegkundigen, werkzaam in hospices, meetinstrumenten gebruiken voor vroegsignalering en monitoren.

Doel en onderzoeksvraag

Met twee onderzoeksvragen is het dagelijks gebruik van meetinstrumenten onderzocht: 'Op welke manier wordt de Lastmeter gebruikt in de dagelijkse hospice praktijk?' Vindt er opvolging plaats met het Utrecht Symptoom Dagboek (USD) en/of USD voor zorgverleners (USD-z)?'

Methode

Door het analyseren van patiënten dossiers zal inzicht worden verkregen in het gebruik van meetinstrumenten. Problemen, geïdentificeerd met de Lastmeter werden onderzocht en scores van het USD/USD-z werden voor iedere patiënt geobserveerd.

Resultaten

Totaal werden er dertig dossiers geanalyseerd. Beschrijvende statistiek liet zien dat de Lastmeter en het USD in bijna de helft van de cases consequent gebruikt werd, en het USD-z bij bijna alle patiënten. Emotionele en lichamelijke problemen werden het meest genoemd. Afkwapwaarden worden niet consequent gebruikt.

Conclusie

Vroegsignalering wordt niet op een consequente manier uitgevoerd in de praktijk. De lastmeter wordt nog niet als standaard zorg ingezet. Monitoren met het USD-z komt het vaakste voor, maar wordt soms beperkt tot specifieke domeinen en vind niet altijd multidimensioneel plaats. Het inzetten van interventies als reactie op een afkwapwaarde wordt niet consequent uitgevoerd.

Aanbevelingen

Verpleegkundigen moeten de Lastmeter, het USD en USD-z consequent gebruiken. Door gebruik te maken van cut point kan verergering van problemen voorkomen worden. Verder onderzoek zal meer inzicht moeten geven in de verschillen tussen scores van patiënten en scores van verpleegkundigen, of er geschikte interventies worden ingezet en de opinie van verpleegkundigen in het gebruik van meetinstrumenten.

Trefwoorden

Palliatieve zorg, vroegsignalering, monitoren, meetinstrumenten, hospices.

English Abstract

From signal to monitoring: early detection in palliative nursing care. A quantitative observational study.

Background

Patients in the palliative phase of their disease experience problems in diverse domains. Symptoms must be multidimensional identified in an early stage and monitored over time to prevent worsening. Measurement instruments are an important tool for identification and monitoring of symptoms. It is unclear in what way measurement instruments for early identification and monitoring are used by nurses, working in daily hospice practices.

Aim and research question

Two research questions examined daily use of instruments: 'In what way is the Distress Thermometer (DT) used in daily high care hospice practice?' Is there a succession with the Utrecht Symptom Diary (USD) and/or Utrecht Symptom Diary for Professionals (USD-p)?'

Method

By analyzing patients dossiers insight was gained into the consistently use of early identification and monitoring, applied with the DT, USD and USD-p. Problems identified with the DT, and the USD/ USD-p scores observed for each patient, were recorded.

Results

A total of thirty dossiers were analyzed. Descriptive statistics showed that in half of the cases the DT and USD were consistently used, the USD-p in almost all cases. Emotional and physical problems were identified most often. Cut points are not consistently used.

Conclusion

Early identification is not deployed in a consistent way in practice. The Distress Thermometer is not used as daily standard care. Monitoring with the aid of the USD-p is most common, but is sometimes limited to specific domains and not multidimensional. Deploying interventions in response to a cut point is not consistently deployed.

Recommendations

Nurses should consistently use the DT, USD and USD-p. Using cut points might avoid crisis care as aggravation of problems can be prevented. Further research is needed to reveal more insight in differences in nurses and patients scores, deploying of suitable interventions and, and the nurses' opinion in using measurement instruments.

Key-words

Palliative care, early detection, monitoring, measurement instruments, hospices