Effect of the Utrecht Symptom Diary on multidisciplinary Symptom Management Performance: A pilot study in glioma patients

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Abstract

Title: Effect of the Utrecht Symptom Diary (USD) on multidisciplinary Symptom Management Performance (SMP): A pilot study in glioma patients.

Background: Patients suffering from cancer have to cope with various symptoms. Adequate symptom management reduces patients' symptom burden and improves quality of life. To improve symptom management the USD was developed for early signaling and monitoring of symptoms. In the USD process intervention patients, nurses and doctors are instructed to use the USD in clinical practice. After development of the intervention, assessing feasibility of study procedures is the next step prior to an effect study.

Aims: The primary objective of this study is to assess the feasibility of study procedures in terms of recruitment and data collection. The secondary objective is to gain insight in preliminary results of the USD process intervention on multidisciplinary SMP.

Method: A pilot study with a cross-sectional design was conducted in glioma patients in a clinical ward. A pre-posttest approach was applied to gain insight into the preliminary results of the USD process intervention on SMP measured by a patient satisfaction questionnaire.

Results: The recruitment rate in this study was 0,58. Patient satisfaction in SMP showed a significant difference in involvement of relatives in symptom treatment, the evaluation of symptom treatment and the nurse's expertise regarding symptoms.

Conclusion: The recruitment rate of 0,58 seemed to be affected by the senior nurse. Patients are satisfied before and after the intervention. Patient satisfaction does not seem be discriminatory enough to indicate a difference in SMP.

Recommendation: Improving the process of identification of eligible patient could improve the recruitment. It is recommended to not include this outcome in the main study. SPM could be approached from other perspectives.

Keywords: Palliative Care, Symptom Assessment, Utrecht Symptom Diary, Patient Satisfaction, Glioma.

Samenvatting

Titel: Het effect van het gebruik van het Utrecht Symptomen Dagboek (USD) op multidisciplinair symptoom management: Een pilot studie bij patiënten met een glioom.
Achtergrond: Patiënten met kanker krijgen te maken met symptomen. Adequaat symptoom management verlaagt symptoomlijden en verbetert kwaliteit van leven. Om symptoom management te verbeteren is het USD ontwikkeld. Binnen de USD proces interventie worden patiënten, verpleegkundigen en artsen geïnstrueerd in het gebruik van het USD. Het nagaan van haalbaarheid van de studieprocedures is een volgende stap voor het uitvoeren van een effectstudie.
Doel: Het primaire doel van deze studie is het nagaan van de haalbaarheid van de procedures van het rekruteren van patiënten en de haalbaarheid van de dataverzameling. Het secondaire doel is het verkrijgen van inzicht in de eerste resultaten van de USD proces interventie op multidisciplinair symptoom management.
Methode: Een pilot studie werd uitgevoerd bij patiënten met glioom, opgenomen op een klinische afdeling. Om inzicht te krijgen in de eerste resultaten van de USD procesinterventie op symptoom management werd een voor- en nameting uitgevoerd. Symptoom management werd gemeten met een patiënttevredenheidsvragenlijst.
Resultaten: 58% van de geschikte patiënten werden gerekruteerd. Patiënttevredenheid over multidisciplinair symptoom management laat een significante verbetering zien ten aanzien van het betrekken van naasten in de symptoombehandeling, het evalueren van symptoombehandeling en verpleegkundige expertise op het gebied van symptomen.
Conclusie: Het betrekken van de senior verpleegkundige in het proces lijkt van invloed op de recruitment. Patiënten zijn tevreden, zowel voor als na de interventie. Patiënttevredenheid lijkt niet discriminerend genoeg voor het aantonen van een verschil.
Aanbeveling: Verbetering van het proces van het identificeren van geschikte patiënten kan recruitment verbeteren. Aanbevolen wordt om de patiënttevredenheidsvragenlijst niet te includeren in de hoofdstudie. Symptoom management kan worden benaderd vanuit andere perspectieven.

Zoekwoorden: Palliatieve Zorg, Symptoom Assessment, Utrecht Symptomen Dagboek, Patiënttevredenheid, Glioom.

INTRODUCTION

Patients suffering from an (incurable) form of cancer have to cope with several symptoms with a fluctuating intensity.[1,2,3,4] These symptoms are a result of their disease or its treatment[5]. A systematic review identified 37 symptoms that nearly all occurred in more than 10% of the patients with incurable cancer. Symptoms like fatigue, loss of strength, pain, lack of energy and loss of appetite occurred in more than 50% of the patients.[2] These symptoms occur in all phases of the disease and have a major impact on the quality of life, quality of treatment and compliance with therapy.[1,4,6,7,8] Optimal care for cancer patients requires managing symptoms across the disease trajectory.[1,2] Adequate symptom management reduces patients' symptom burden and is essential for improvement in both quality of life and mood of the patient.[9,10]

In patients with cancer, symptom management can be described as a dynamic and multidimensional process of analysis and treatment of symptoms, evaluation of the effect and adjustment of policies if required.[11,12,13] Caregivers frequently underestimate the symptom burden and symptoms are frequently not recognized or treated.[6,14] Inadequately treated symptoms lead to unnecessary discomfort for the patient.[6,7]

Four steps, known as palliative reasoning, describes a methodology of decision making regarding symptom management.[12] These steps are assessment of symptoms, performing interventions, monitoring, and evaluating symptom treatment and should be routine aspects of symptom management delivered by any professional.[6, 7,8 12,15] To provide adequate symptom management and reduce symptom burden, a multidisciplinary approach is necessary[7].

To improve assessment, monitoring and evaluation of treatment of symptoms, the Utrecht Symptom Diary (USD) has been developed. The USD is a patient reported outcome measure derived from the internationally used Edmonton Symptom Assessment Scale[9,16,17]. Since 2002, the USD has been used for patients with cancer at the department of medical oncology, starting in a palliative population[18]. The USD asks patients to self-asses eleven symptoms and their wellbeing on a daily basis, by using a numerical rating scale ranging from 0 to 10. Patients can also indicate which symptom is a priority for them. The diary is now a validated instrument for patients with cancer in all phases of the disease[18].

In the following years, tumor- and treatment-specific USD modules were developed complementary to the basic set op symptoms on the core USD. Any type of cancer is related to tumor specific symptoms.[18] This especially holds for glioma patients, who mainly suffer from neurological symptoms. In 2015, the prevalence of glioma patients in the Netherlands was 2885 patients.[19] The majority of patients with a glioma experience symptoms like loss of consciousness, epileptic seizures, headaches, motor deficits, aphasia and difficulties swallowing.[20,21] Neurological and cognitive deficits show progression in the end-of-life phase.

In 2016, a complementary module of the USD for glioma patients, called the USD-glioma, was developed (Appendix A). Seven disease-specific symptoms were added to the USD core version, based on a review of the literature, expert opinion and patient interviews.

The increasing use of the USD in daily practice indicates positive experiences. However, effects on symptom care have not been researched. Internationally, several studies investigated using the ESAS as a measuring instrument for symptom prevalence.[16,17] Testing the ESAS as an intervention for improvement of symptom management is mainly performed in outpatient settings.[9,22]

A research is set up to test the effect of the USD process intervention on symptom management performance of the multidisciplinary team (MT) in clinical patients. In the USD process intervention, patients, nurses and doctors are instructed to use the USD in clinical practice. The definition for SMP in this study is “all diagnostic, therapeutic or coordinative interventions carried out by the multidisciplinary team to alleviate multidimensional suffering of patients and family members”.[9]

To determine whether the USD intervention with tumor-specific USD’s affects SMP, a pre-posttest was carried out. According to the definition of the Medical Research Council (MRC), the USD process intervention is a complex intervention.[23] It contains several interacting components within the intervention, complex patient categories and a number of involved multidisciplinary groups.[23] This complex intervention needs an approach according to the MRC model, which means assessing feasibility and piloting after developing the intervention, prior to a larger-scale research.[23,24,25] A pilot study assesses whether the components of the lager main study can all work together.[23,24,26,27]

AIMS

The primary objective of this pilot study is to assess the feasibility of the study procedures of recruitment and data collection for testing the USD process intervention in glioma patients in a clinical setting. The secondary objective is to gain insight into first effect of the USD process intervention for admitted glioma patients on patient satisfaction in SMP of the MT.

METHODS

Design

A pilot study with a cross-sectional design was performed between August 2016 and May 2017. The primary outcomes of this study are the feasibility of procedures of recruitment and data collection. To gain insights into the first effect of the USD process intervention, a pre-posttest approach was applied with assessment of SMP pre- and post-intervention. Data was collected in the eleven weeks pretest period and ten weeks posttest period. During the first week of the pretest period, a pilot patient satisfaction questionnaire was used. Figure 1 gives

an overview of the study design. For this report, the STrengthening the Reporting of OBservational studies in Epidemiology (STROBE) statement was used.[28,29]

{Figure 1}

Population and recruitment

Glioma patients admitted to the neuro-oncology ward of a University Medical Hospital in the Netherlands in both research periods were asked to participate in this study. To participate, the following inclusion criteria were used: (A) diagnosis of a glioma or suspicion of a glioma in (B) people aged 18 years or older, (C) able to answer questions, (D) able to communicate in Dutch and (E) having admission duration of at least 48 hours. Patients were approached by the researcher after daily telephone consultation of the researcher with a senior nurse on the ward. The nurse identified patients who were eligible for the research according to the inclusion criteria and a planned discharge from hospital within two weeks. These senior nurses received information about the research prior to the research period.

Intervention

The USD process intervention consists of implementing the USD glioma in multidisciplinary daily practice. The implementation period started in November 2016, led by a project team. Using the USD in daily practice started on December 1st 2016. The following steps were performed:

- Training nurses in using the USD.
- Informing doctors about using the USD.
- Nurse instructing to fill in the USD-glioma.
- Written instruction for patients provided on the backside of the USD.
- Nurse and patient discussing the outcomes of the USD.
- Discussing the outcomes of the USD during the doctors' daily visit and in MT meetings.
- Reporting symptoms and their treatment.

Ethical considerations

This study was performed according to the declaration of Helsinki[30], principles of good clinical practice[31], the Dutch law in general and the Medical Research Involving Human Subjects Acts (WMO). The Medical Ethics Committee (METC) confirmed that WMO permission was not necessary (METC number: 16/509). Data from patient records were

gathered on location, anonymized and coded. Patients received verbal and written information about the study. Verbal informed consent was obtained.

Data collection

Feasibility outcomes

Recruitment: To assess the recruitment procedure, an eligibility rate by the nurse, exclusion rate, recruitment rate and response rates were determined. The eligibility rate by the nurse was calculated as the proportion of those meeting the inclusion criteria who were identified as eligible for the research by senior nurses. To gain insights into this eligibility rate, the admission list of the neuro-oncology ward regarding the research period was obtained. From this list, eligible patients were selected based on a diagnosis of glioma or a suspicion of a glioma, aged 18 years old or older and with admission duration of at least 48 hours. The exclusion rate was calculated as the proportion of patients identified by the senior nurses who were not meeting the inclusion criteria. The recruitment rate was calculated as the proportion of those meeting the inclusion criteria who gave informed consent.

A recruitment of 2/3 (67%) of eligible patient was seen as an adequate outcome. This percentage was chosen because patients can easily be missed by the researcher, due to absence on the ward or sudden discharge from hospital. In addition, identification takes place by the senior nurse on the ward, so possibly not all eligible patients are identified. The informed consent rate was determined as the proportion of patients asked for participation who gave informed consent. During the research period, a logbook was kept to gain insight into the recruitment procedure.

Data collection: To assess whether the data collection procedure was feasible, the unit response rate and item non-response were determined. The unit response rate was calculated as the proportion of patients who gave informed consent and filled in the questionnaire. Item non-response (missing data) refers to questions the patients did not answer.[32] To evaluate feasibility of the questions, patients in posttest period were asked whether the questions on this questionnaire were clearly formulated at the end of the questionnaire.

Clinical outcomes

The secondary outcome is patient satisfaction in SMP by the MT. SMP was formulated as *"all diagnostic, therapeutic or coordinative interventions carried out by the multidisciplinary team to alleviate multidimensional suffering of patients and family members."*[9] An SMP checklist (Appendix A) was developed for this study based on literature, clinical expertise and expert opinions. The checklist includes items for adequate SMP. To make SMP operational, a questionnaire for patient satisfaction in SMP (Figure 2) was developed. In formulating the

questions, available measurement instruments for symptom management were used (FAMCARE-p13[33,34], CQI Palliative Care[35]). The questionnaire was checked for face validity by the same team as involved in the SMP checklist. After one week of the pilot questionnaire and adjustments, the final questionnaire was used. Steps in development of the patient satisfaction in SMP questionnaire are described in Figure 2.

The questionnaire contains thirteen questions—ten general questions and three symptom-specific questions. Patient satisfaction in SMP was measured on a 5-point Likert scale. Patients could explain their answers or other comments about the symptom care they received. The questionnaires were given as an interview by the researcher or the patient filled in the questionnaire. The required sample size was 30 recruited participants for each group, both pretest and post-intervention. In pilot studies, it is a general rule to take 30 people for each group.[36,37,38]

{Figure 2}

Data analysis

Feasibility outcomes

To analyze the primary and secondary outcomes, descriptive statistics were employed using the IBM SPSS, V.22 (IBM Corporation, UK). Eligibility rate by nurse, exclusion rate, recruitment rate and response rates were calculated in proportions. The feasibility of questions in the patient satisfaction questionnaire was analyzed by describing the questions that were referred to as difficult by the patient. Analysis was conducted by two researchers (SH and MI).

Clinical outcome—patient satisfaction in SMP

Patient characteristics were analyzed using descriptive statistics. Patient satisfaction, measured on a 5 point Likert-scale (ordinal data), was analyzed using a Mann-Whitney test.[48,49] This nonparametric test was used to detect differences in patient satisfaction in SMP in the pretest and posttest groups (unpaired groups).[48,49] A level of $\alpha = .05$ was used to determine statistical significance; thus $p < 0.05$ was considered statistically significant. Additionally, a subgroup analysis was performed on patient satisfaction in surgical patients and patients admitted with a functional decline or other symptom burden. Care-related comments were analyzed by two researchers (SH and MI).

RESULTS

This pilot study included 59 patients—33 patients in pretest period and 26 patients in posttest period. Patients in this study were on average 57,8 years old and 57.6% were male.

Admission indications are; surgical resection or debulking of a glioma tumor (in some cases combined with diagnostic when diagnose is not yet definitive), diagnostic and functional decline, or other symptom burden. Surgical treatment was the most common admission reason (55.9%). Patient characteristics are described in Table 1.

{Table 1}

Primary outcomes—recruitment procedure

Eligibility by the nurse: In the total research period, 281 patients were admitted to the neuro-oncology ward. Based on the admission list, patients were evaluated for the following criteria: (A) admitted with a glioma or suspicion of glioma, (B) aged above 18 years and (E) admission duration of at least 48 hours. 123 patients met these criteria. Eight patients could not answer questions (C) and two patients were unable to communicate in Dutch (D). 113 patients were eligible. The senior nurse identified 77 (68%) of these patients as eligible to participate in this study. Therefore, the eligibility rate by the nurse was 0,68.

Exclusion rate: 96 patients were listed as potential participants by the senior nurse. Nineteen patients (19.8%) were excluded from this study. Eight patients had an admission reason besides glioma or suspicion of glioma, two patients were unable to speak Dutch, eight patients could not answer questions and one patient had admission duration of less than 48 hours. The exclusion rate was 0,20. Of these patients, 42.1% were excluded based on their cognition.

Informed consent rate: 77 eligible patients were noted by the senior nurse. Nine of these patients were missed by the researcher because they were already discharged or not present at the ward. 65 (95.6%) of the 68 patients who were asked to participate gave informed consent. Three patients did not want to participate. Two patients found it too stressful to participate in the research and one patient did not want to participate. The response rate for informed consent was 0,96

Recruitment rate: 113 patients were eligible to participate in this study. Finally, 65 patients (57.5%) gave informed consent. Therefore, the recruitment rate was 0,58.

Figure 3 presents an overview of primary outcomes of the recruitment procedure.

{Figure 3}

Primary outcomes – data collection procedure

Unit response rate: In total, 65 patients received the patient satisfaction in SMP questionnaire. 59 patients (90.8%) responded. Therefore, the unit response rate is 0,91. Of the 59 questionnaires, 32 were given as an interview. The other 27 patients filled in the

questionnaire. Nine of the patients filled in or answered the questionnaire together with their relatives.

Eight of the 59 patients filled in the pilot questionnaire. These pilot questionnaires missed two questions in comparison to the final questionnaire. All completed answers are included in the analysis of patient satisfaction in SMP. Of the 51 remaining questionnaires, 47 were filled in completely. In each incomplete questionnaire, a different question is unanswered. 18.7% of the questions were answered with 'unknown'. 'Unknown' is most seen (>10) in question 3 (referrals to experts), question 7 (extent to which treatment is evaluated) and questions 11–13 (regarding attention for specific symptoms).

Feasibility of questions: In the posttest period, item 14 was added to the questionnaire. The item was: 'Are there questions in this questionnaire that you found unclear or difficult to answer? If so, which and why?' 26 patients received this extra question. Seven patients did not fill in this question. Thirteen patients answered the question with 'no'. Six patients named one or more questions as unclear or difficult. These were questions five and six (n = 1) regarding involving relatives, question 7 (n = 1) regarding evaluation of treatment, and questions eleven to thirteen (n = 3) regarding attention to specific symptoms. Another patient indicated that he understands the questions when read with the researcher's explanation.

Both in the pretest and posttest period, patients could explain their answers or give other comments about the symptom care they received as final item on the questionnaire. The comments can be distinguished in care-related comments and procedural comments. Sixteen procedural comments (Appendix C) were given.

In the procedural comments, eight patients answered 'not applicable' to several questions. This is especially seen in questions 11–13 regarding attention for specific symptoms. Patients indicated that they do not suffer from the symptom. Three patients noted they could not remember everything that happened during admission. 50% of the procedural comments were given when the questionnaire was taken as an interview.

Secondary outcome—patient satisfaction in SMP

On average, patients are satisfied to very satisfied with SMP of the MT in both pretest and posttest periods. The analysis of the patient satisfaction questionnaires pretest and posttest showed a significant (P<,05) difference in patient satisfaction in three questions. This applied to questions six, seven and eight (Table 2). Question six asked patients about how involved relatives were in symptom treatment. Question seven was about how much the symptom treatment helped. In question eight, the nurse's expertise regarding symptoms was evaluated. Subgroup analysis in surgical patients (n = 47) and patient admitted with a functional decline or other symptom burden (n = 18) showed a significant difference. However, the groups are too small to mention this.

{Table 2}

In total, 79 care-related comments were made—49 in the pretest period and 30 in posttest period. 94.9% of the care-related comments were made when the questionnaire was given as an interview. During the pretest period, more negative comments (39/49) were made about symptom care than during posttest period (15/29). This mainly concerns the attention to the specific symptoms complaints of distress, concentration and memory complaints, and epileptic seizures. Five patients in the pretest period indicated that no attention was given or it was given too late. Overall, seven patients indicated that the overall expertise of the doctor and nurse was good, except for some individual professionals. Seven patients indicated that they think they received less care or attention due to their problems with cognition.

DISCUSSION

This study assessed the feasibility of recruitment and data collection for evaluating the effect of the USD process intervention in glioma patients. 113 eligible patients with glioma or suspicion of glioma were admitted in a 21-week period. The eligibility rate by the nurse for this study was 0,68. The senior nurse seemed to play a role in missing patients for this study. Caregivers sometimes prevent assessment of eligible patients for research recruitment, known as 'gatekeeping'.[50,51] Some patients were missed by the researchers or did not want to participate. Overall, the recruitment rate was 0,58. The exclusion rate in this study was 0,20. Many patients were excluded based on their cognition (42.1%). In identifying patients by the senior nurse, problems with cognition were common. More than 50% of the patients received the questionnaire as an interview. This resulted in more procedural and care-related comments from these patients. Patients indicated that they did not see the answer option "not applicable" in the patient satisfaction questionnaire.

The secondary objective was to gain insight into first effect of the USD process intervention for admitted glioma patients on patient satisfaction in SMP of the MT. Before and after the USD process intervention, patients showed a significant difference in patient satisfaction in the involvement of relatives in the treatment of symptoms, the evaluation of treatment of symptoms and the nurse's expertise regarding symptoms. Patients regularly fill in the USD with relatives, which could lead to increased involvement of relatives. Daily completing the USD and discussing the outcomes with the nurse can lead to more evaluation of treatment[9,22] and possible more patient satisfaction with evaluation of treatment.

To appreciate the findings of this study, some aspects require further consideration. The current study has some limitations. First, generalizability is limited. Patients with a neurological disorder have more problems with cognition than patients with a non-neurological disorder.[20,52,53,54] This could have positive effect on recruitment rate in other

patient groups. In other patient populations, there will probably be less exclusion based on impaired cognition. Second, based on admission list, it was not possible to exclude patients with impaired cognition or speaking another language than Dutch. The number of eligible patients in this study based on the admission list may be too high. This may have a negative influence on the eligibility rate by nurses and on the recruitment rate. Third, when the patient satisfaction questionnaire is taken as an interview, patients might give socially desirable answers.[55] This could bias the results. However, this also has the advantage of patients giving more critical notes about care.

The strength of the present study is the insight obtained into the feasibility for performing the main study in a complex patient group.[20,52,53,54] The outcomes give insight into the feasibility of recruitment and data collection and steps needed to perform the main study. Strength of this study is a personal approach to patients. The high informed consent rate and high response rate for the patient satisfaction questionnaire could be due to personal approach during data collection.[56,57]

The goal of a 67% recruitment rate was not achieved in this study. Recruitment of patients with advanced illness in clinical studies is complex and challenging.[50,51] Golla et al. showed a recruitment rate of 58% in a pilot study in glioma patients.[58] Study samples are smaller than desired in other research in palliative care as wel.[50,51,59-61] Some studies are prematurely terminated without having enrolled a single patient.[50,62] Patient satisfaction is not discriminatory enough to indicate an effect on SMP. Patients are satisfied to very satisfied with SMP of the MT in both pretest and posttest periods. Patient satisfaction has a ceiling effect.[63] Patients appeared to quickly achieve a high level of satisfaction. Other patient satisfaction studies show that an effect of an intervention on patient satisfaction is difficult to indicate.[63,64]

For researchers, the results of this study provide insight into adjustments to make in procedures of recruitment and data collection. Policymakers or managers can decide to implement the USD and to participate in the main study based on the on the outcomes in the current study. This means that the senior nurses' role within the research will remain important.

The results of this pilot study show that the procedure for recruitment and data collection is not yet feasible for running the main study. Based on the (cognitive) complexity of glioma patients, recruitment of more than 58% of eligible patients will be feasible in the main study performed in other patient groups. However, the study protocol would need to be adjusted. Improving the process of identification of eligible patients by the senior nurse could improve the recruitment rate. A patient satisfaction questionnaire does not seem to indicate a difference in SMP pretest and posttest. It is recommended to not include this outcome in the main study. Patients' care-related comments on the patient satisfaction questionnaire are

interesting. SPM could be approached from other perspectives, like patient file research[65] or the experience of professionals.

REFERENCE LIST

1. Seow H, Barbera L, Sutradhar R, Howell D, Dudgeon D, Atzema C, et al. Trajectory of performance status and symptom scores for patients with cancer during the last six months of life. J Clin Oncol 2011;29(9):1151-1158.
2. Teunissen, Saskia C C M, Wesker W, Kruitwagen C, de Haes, Hanneke C J M, Voest E, de Graeff A. Symptom prevalence in patients with incurable cancer: a systematic review. J Pain Symptom Manage 2007;34(1):94-104
3. Spichiger E. Symptom prevalence and changes of symptoms over ten days in hospitalized patients with advanced cancer: a descriptive study. European journal of oncology nursing 2011;15(2):95.
4. Deshields T, Potter P, Olsen S, Liu J, Dye L. Documenting the symptom experience of cancer patients. J Support Oncol 2011;9(6):216-223.
5. Dodd M. Advancing the science of symptom management. J Adv Nurs 2001;33(5):668.
6. Beuken-van,M H J van den. Quality of life and non-pain symptoms in patients with cancer. J Pain Symptom Manage 2009;38(2):216.
7. Henry DH. Symptoms and treatment burden associated with cancer treatment: results from a cross-sectional national survey in the US. Supportive Care in Cancer 2008;16(7):791.
8. Lancker, A van. Prevalence of symptoms in older cancer patients receiving palliative care: a systematic review and meta-analysis. J Pain Symptom Manage 2014;47(1):90.
9. Strasser F, Blum D, von Moos R, Cathomas R, Ribi K, Aebi S, et al. The effect of real-time electronic monitoring of patient-reported symptoms and clinical syndromes in outpatient workflow of medical oncologists: E-MOSAIC, a multicenter cluster-randomized phase III study (SAKK 95/06). Ann Oncol 2016;27(2):324-332.
10. Temel J, Greer J, Muzikansky A, Gallagher E, Admane S, Jackson V, et al. Early palliative care for patients with metastatic non-small-cell lung cancer. N Engl J Med 2010;363(8):733-742.
11. Fu M, LeMone P, McDaniel R. An integrated approach to an analysis of symptom management in patients with cancer. Oncol Nurs Forum 2004;31(1):65-70.
12. Intergraal Kanker Centrum Nederland (IKNL). Richtlijn: Algemene principes van palliatieve zorg [document on the internet]. Pallialine; 2016 [updated 2016 September 1, cited 2017 March 3] Available from:

http://www.netwerkpalliatievezorg.nl/Portals/44/Algemene%20principes%20van%20palliatieve%20zorg%20%282%29%20IKNL%202016_1.pdf.
13. de Graeff A, Jobse AP, Teunissen SCCM, Verkuijlen MMJD, Vissers KCP, Zylicz Z, Gilsing MG. Algemene principes van palliatieve zorg. Nederlands Tijdschrift voor Oncologie (NTVO). 2017;14(2):62-65.
14. Morrison RS. Palliative care. N Engl J Med 2004;350(25):2582.
15. Quill T, Abernethy A. Generalist plus specialist palliative care--creating a more sustainable model. N Engl J Med 2013;368(13):1173-1175.
16. Richardson LA, Jones GW. A review of the reliability and validity of the Edmonton Symptom Assessment System. Curr Oncol 2009;16(1):55-55.
17. Nekolaichuk C. The Edmonton Symptom Assessment System: a 15-year retrospective review of validation studies (1991–2006). Palliat Med 2008;22(2):111.
18. de Nijs , Echteld MA, Westers P, de Graeff A, Voest EE, Teunissen SCCM. The Utrecht Symptom Diary: measurement properties of the Dutch modified Edmonton Symptom Assessment System. [Submitted], 2016.
19. Intergraal Kankercentrum Nederland (IKNL). Nederlandse Kankerregistratie; cijfers over kanker [document on the internet]. Utrecht, 2016. [updated 2017 February 2] Available from: http://www.cijfersoverkanker.nl/
20. Sizoo E, Braam L, Postma T, Pasman HRW, Heimans J, Klein M, et al. Symptoms and problems in the end-of-life phase of high-grade glioma patients. Neuro-oncology 2010;12(11):1162-1166.
21. Osoba D, Brada M, Prados MD, Yung WK. Effect of disease burden on health-related quality of life in patients with malignant gliomas. Neuro-oncology 2000;2(4):221-228.
22. Hoekstra J, de Vos R, van Duijn N, Schadé E, Bindels PJE. Using the symptom monitor in a randomized controlled trial: the effect on symptom prevalence and severity. J Pain Symptom Manage 2006;31(1):22-30
23. Craig P, Dieppe P, Macintyre S, Michie S, Nazareth I, Petticrew M. Developing and evaluating complex interventions: the new Medical Research Council guidance. BMJ 2008;337:a1655-a1655.
24. Whitehead A, Sully BGO, Campbell M. Pilot and feasibility studies: is there a difference from each other and from a randomised controlled trial? Contemp Clin Trials 2014;38(1):130-133.
25. Lancaster GA. Design and analysis of pilot studies: recommendations for good practice. J Eval Clin Pract 2004;10(2):307.
26. Thabane L, Ma J, Chu R, Cheng J, Ismaila A, Rios L, et al. A tutorial on pilot studies: the what, why and how. BMC Med Res Methodol 2010;10:1-1.

27. Eldridge S. Definition and reporting of pilot and feasibility studies. Trials 2013;14(1):1.
28. Vandenbroucke J. STREGA, STROBE, STARD, SQUIRE, MOOSE, PRISMA, GNOSIS, TREND, ORION, COREQ, QUOROM, REMARK... and CONSORT: for whom does the guideline toll? J Clin Epidemiol 2009;62(6):594-596.
29. Vandenbroucke J, von Elm E, Altman D, Gøtzsche P, Mulrow C, Pocock S, et al. Strengthening the Reporting of Observational Studies in Epidemiology (STROBE): explanation and elaboration. Int J Surg 2014;12(12):1500-1524.
30. WORLD MEDICAL ASSOCIATION DECLARATION OF HELSINKI. Ethical Principles for Medical Research Involving Human Subjects. 1964 [updated 2013 October 19, cited 2017 May 2]. Available from: https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/
31. World Health Organization. Handbook for good clinical research practice (GCP): guidance for implementation. 2005 [cited 10 May 2017]. Avaliable from: http://whq libdoc.who.int/publications/2005/924159392X_eng. pdf
32. Barriball KL, While AE. Non-response in survey research: a methodological discussion and development of an explanatory model. J Adv Nurs 1999;30(3):677-686.
33. Lo C, Burman D, Hales S, Swami N, Rodin G, Zimmermann C. The FAMCARE-Patient scale: measuring satisfaction with care of outpatients with advanced cancer. Eur J Cancer 2009;45(18):3182-3188.
34. Lo C, Burman D, Rodin G, Zimmermann C. Measuring patient satisfaction in oncology palliative care: psychometric properties of the FAMCARE-patient scale. Qual Life Res 2009;18(6):747-752.
35. Wessels, H. Needs and preference of patients with cancer. Utrecht: Utrecht University, the Netherlands; 2010.
36. Browne RH. On the use of a pilot sample for sample size determination. Stat Med 1995;14(17):1933-1940.
37. Hertzog M. Considerations in determining sample size for pilot studies. Res Nurs Health 2008;31(2):180-191.
38. Teare MD. Sample size requirements to estimate key design parameters from external pilot randomised controlled trials: a simulation study. Trials 2014;15(1):1.
39. Claessen SJJ, Francke A, Sixma H, de Veer AJE, Deliens L. Measuring patients' experiences with palliative care: the Consumer Quality Index Palliative Care. BMJ Support Palliat Care 2012;2(4):367-372.
40. Brant JM. Building dynamic models and theories to advance the science of symptom management research. J Adv Nurs 2010;66(1):228.

41. Blum D, Rosa D, deWolf Linder S, Hayoz S, Ribi K, Koeberle D, et al. Development and validation of a medical chart review checklist for symptom management performance of oncologists in the routine care of patients with advanced cancer. J Pain Symptom Manage 2014;48(6):1160-1167.
42. Chan M. An online Symptom Care and Management System to monitor and support patients receiving chemotherapy: A pilot study. Int J Nurs Pract 2013;18:14.
43. Cohen E, Botti M. Cancer Patients' Perceptions of the Barriers and Facilitators to Patient Participation in Symptom Management During an Episode of Admission. Cancer Nurs 2015;38(6):458-465.
44. Jablonski A. A model for identifying barriers to effective symptom management at the end of life. Journal of hospice and palliative nursing 2005;7(1):23.
45. Kittelson S. Palliative Care Symptom Management. ; 2015. p. 315-339.
46. Lee Y. A systematic review of the effectiveness of problem-solving approaches towards symptom management in cancer care. J Clin Nurs 2011;20(1/2):73.
47. Shoemaker L, Estfan B, Induru R, Walsh TD. Symptom management: an important part of cancer care. Cleve Clin J Med 2011;78(1):25-34.
48. De Winter JCF. Five-point Likert items: t test versus Mann-Whitney-Wilcoxon. Practical assessment, research & evaluation 2010;15(11):1.
49. Field A. Discovering statistics using IBM SPSS statistics. 4Th ed. London: Sage publications; 2013. P.217-219.
50. Kars M, van Thiel G, van der Graaf R, Moors M, de Graeff A, van Delden J. A systematic review of reasons for gatekeeping in palliative care research. Palliat Med 2016;30(6):533-548.
51. Ewing G, Rogers M, Barclay S, McCabe J, Martin A, Todd C. Recruiting patients into a primary care based study of palliative care: why is it so difficult? Palliat Med 2004;18(5):452-459.
52. Kayl A, Meyers C. Does brain tumor histology influence cognitive function? Neuro-oncology 2003;5(4):255-260.
53. Taphoorn MJB, Klein M. Cognitive deficits in adult patients with brain tumours. Lancet Neurol 2004;3(3):159-168.
54. Habets EJJ, Kloet A, Walchenbach R, Vecht C, Klein M, Taphoorn MJB. Tumour and surgery effects on cognitive functioning in high-grade glioma patients. Acta Neurochir (Wien) 2014;156(8):1451-1459.
55. Bowling A. Mode of questionnaire administration can have serious effects on data quality. J Public Health (Oxf) 2005;27(3):281-291.

56. Treweek S, Pitkethly M, Cook J, Kjeldstrøm M, Taskila T, Johansen M, et al. Strategies to improve recruitment to randomised controlled trials. Cochrane Database Syst Rev 2010(4):MR000013-MR000013.
57. Hunt K, Shlomo N, Addington Hall J. Participant recruitment in sensitive surveys: a comparative trial of 'opt in' versus 'opt out' approaches. BMC Med Res Methodol 2013;13:3-3.
58. Golla H, Ale Ahmad M, Galushko M, Hampl J, Maarouf M, Schroeter M, et al. Glioblastoma multiforme from diagnosis to death: a prospective, hospital-based, cohort, pilot feasibility study of patient reported symptoms and needs. Support Care Cancer 2014;22(12):3341-3352.
59. Gibbins J, Reid C, Bloor S, Burcombe M, McCoubrie R, Forbes K. Overcoming barriers to recruitment in care of the dying research in hospitals. J Pain Symptom Manage 2013;45(5):859-867.
60. McMillan S, Weitzner M. Methodologic issues in collecting data from debilitated patients with cancer near the end of life. Oncol Nurs Forum 2003;30(1):123-129.
61. Hanratty B, Lowson E, Holmes L, Addington Hall J, Arthur A, Grande G, et al. A comparison of strategies to recruit older patients and carers to end-of-life research in primary care. BMC Health Serv Res 2012;12:342-342.
62. Buss M, Arnold R. Challenges in palliative care research: one experience. J Palliat Med 2004;7(3):405-407.
63. Moret L. Improvement of psychometric properties of a scale measuring inpatient satisfaction with care: a better response rate and a reduction of the ceiling effect. BMC Health Services Research 2007;7(1):197.
64. Berning V, Laupheimer M, Nübling M, Heidegger T. Influence of quality of recovery on patient satisfaction with anaesthesia and surgery: a prospective observational cohort study. Anaesthesia 2017.
65. 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 Support Palliat Care 2017.

TABLES AND FIGURES

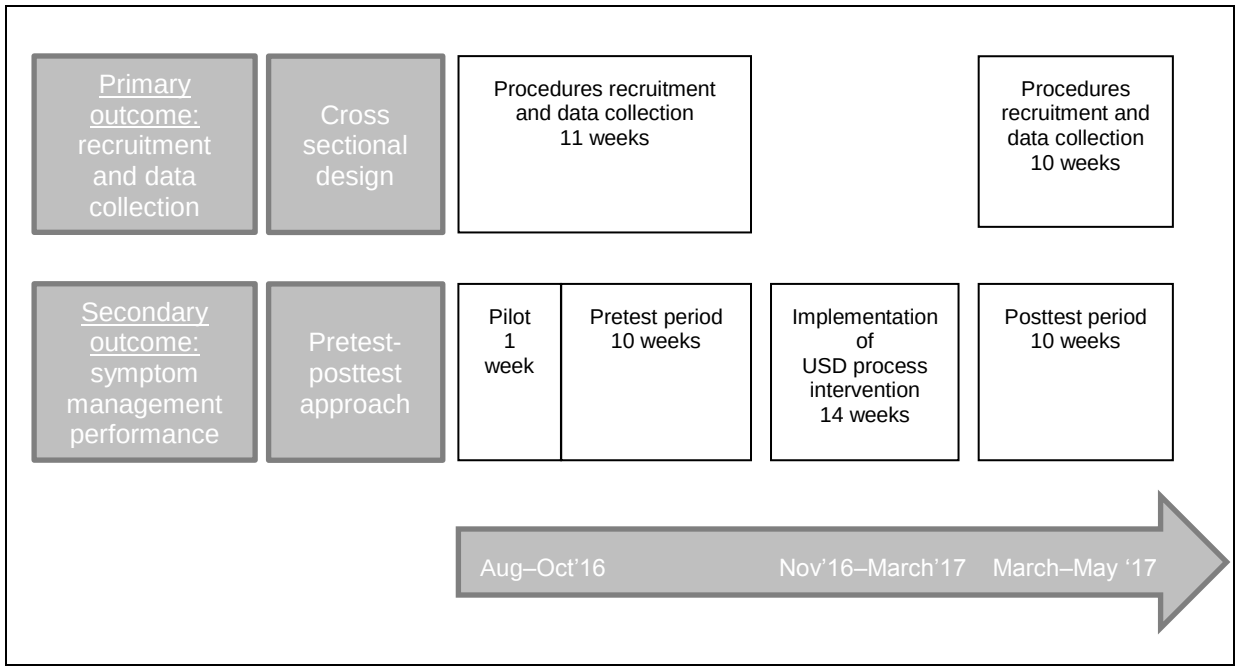

Figure 1 Overview study design

Question		Satisfaction					
1.	The attention for assessment of your symptoms and side effects by doctors and nurses?	Very dissatisfied	Dissatisfied	Satisfied nor dissatisfied	Satisfied	Very satisfied	Unknown
2.	The speed of assessment of your symptoms and side effects?	Very dissatisfied	Dissatisfied	Satisfied nor dissatisfied	Satisfied	Very satisfied	Unknown
3.	Referrals to experts when difficulties in treating symptoms or side effects? (For example: specialized doctors or nurses, physical therapy, psychologist)?	Very dissatisfied	Dissatisfied	Satisfied nor dissatisfied	Satisfied	Very satisfied	Unknown
4.	Given information about symptoms and side effects?	Very dissatisfied	Dissatisfied	Satisfied nor dissatisfied	Satisfied	Very satisfied	Unknown
5.	The extent to which you are involved in the decisions made about the treatment of your symptoms and side effects?	Very dissatisfied	Dissatisfied	Satisfied nor dissatisfied	Satisfied	Very satisfied	Unknown
6.	The extent to which your relative is (potentially) involved in the treatment of your symptoms and side effects?	Very dissatisfied	Dissatisfied	Satisfied nor dissatisfied	Satisfied	Very satisfied	Unknown
7.	The extent of evaluation if treatment of your symptoms and side effects actually helps?	Very dissatisfied	Dissatisfied	Satisfied nor dissatisfied	Satisfied	Very satisfied	Unknown
8.	The nurse's expertise regarding your symptoms and side effects?	Very dissatisfied	Dissatisfied	Satisfied nor dissatisfied	Satisfied	Very satisfied	Unknown
9.	Doctors' expertise regarding care for your symptoms and side effects?	Very dissatisfied	Dissatisfied	Satisfied nor dissatisfied	Satisfied	Very satisfied	Unknown
10.	The extent to which your various healthcare providers are aware of the treatment of your symptoms and side	Very dissatisfied	Dissatisfied	Satisfied nor dissatisfied	Satisfied	Very satisfied	Unknown

	effects by interdisciplinary consultation?						
11.	The attention for complaints of distress?	Very dissatisfied	Dissatisfied	Satisfied nor dissatisfied	Satisfied	Very satisfied	Unknown
12.	The attention for epileptic seizures?	Very dissatisfied	Dissatisfied	Satisfied nor dissatisfied	Satisfied	Very satisfied	Unknown
13.	The attention for concentration and memory complaints?	Very dissatisfied	Dissatisfied	Satisfied nor dissatisfied	Satisfied	Very satisfied	Unknown
14.	Are there any questions in this questionnaire that you found unclear or difficult to answer? If so, which questions and why?						

Room for explanatory notes about the questions or other comments about the care of your symptoms and side effects (you can also use the backside of this form)

Steps in development of the patient satisfaction in SMP questionnaire:

1. Literature search (SH): The databases PubMed, Embase, CINAHL, and the Cochrane Library were searched. The following search/MeSH terms were used: symptom management, palliative care, checklist symptom management, symptom management model and symptom management theory. Data about SMP from multiple articles were added[5,33-47].
2. Use of available measurement instruments for symptom management: FAMCARE-p13[33,34], Patient Priority Piramide[35] and Consumer Quality Index (CQI) Palliative Care[39]
3. Clinical expertise (MI)
4. Expert opinion: The experts were two nurse practitioners in palliative care, two internist oncologists, one professor of palliative care and three oncology nurses/researchers.
5. Face validity: Face validity was reached by a professor of palliative care and three oncology nurses/researchers.
6. Pilot questionnaire: the pilot questionnaire was modified after one week use into a final patient satisfaction in the SMP questionnaire.

Figure 2 Patient satisfaction in SMP questionnaire

Table 1 Patient characteristics

Variable	Mean	Range	Pretest (N=33)	Posttest (N=26)
Age	57,8	24-77	59,8 (29-77)	55,23 (24-77)
Gender				
Female, N (%)	25 (42.4%)	-	14 (42.4%)	11 (42.3%)
Male, N (%)	34 (57.6%)	-	19 (57.6%)	15 (57.7%)
Duration of admission (days)	8	2-41	8,4 (2-41)	7,5 (2-21)
Diagnosis, N (%)				
Glioma	27 (45.8%)	-	14 (42.4%)	13 (50.0%)
Suspicion of glioma	32 (54.2%)	-	19 (57.6%)	13 (50.0%)
Reason for admission to hospital (%)	11 (18.6%)	-	7 (21.2%)	4 (15.4%)
Diagnostics	33 (55.9%)	-	16 (48.5%)	17 (65.4%)
Surgical treatment	15 (25.4%)	-	10 (30.3%)	5 (19.2%)
Symptom treatment				

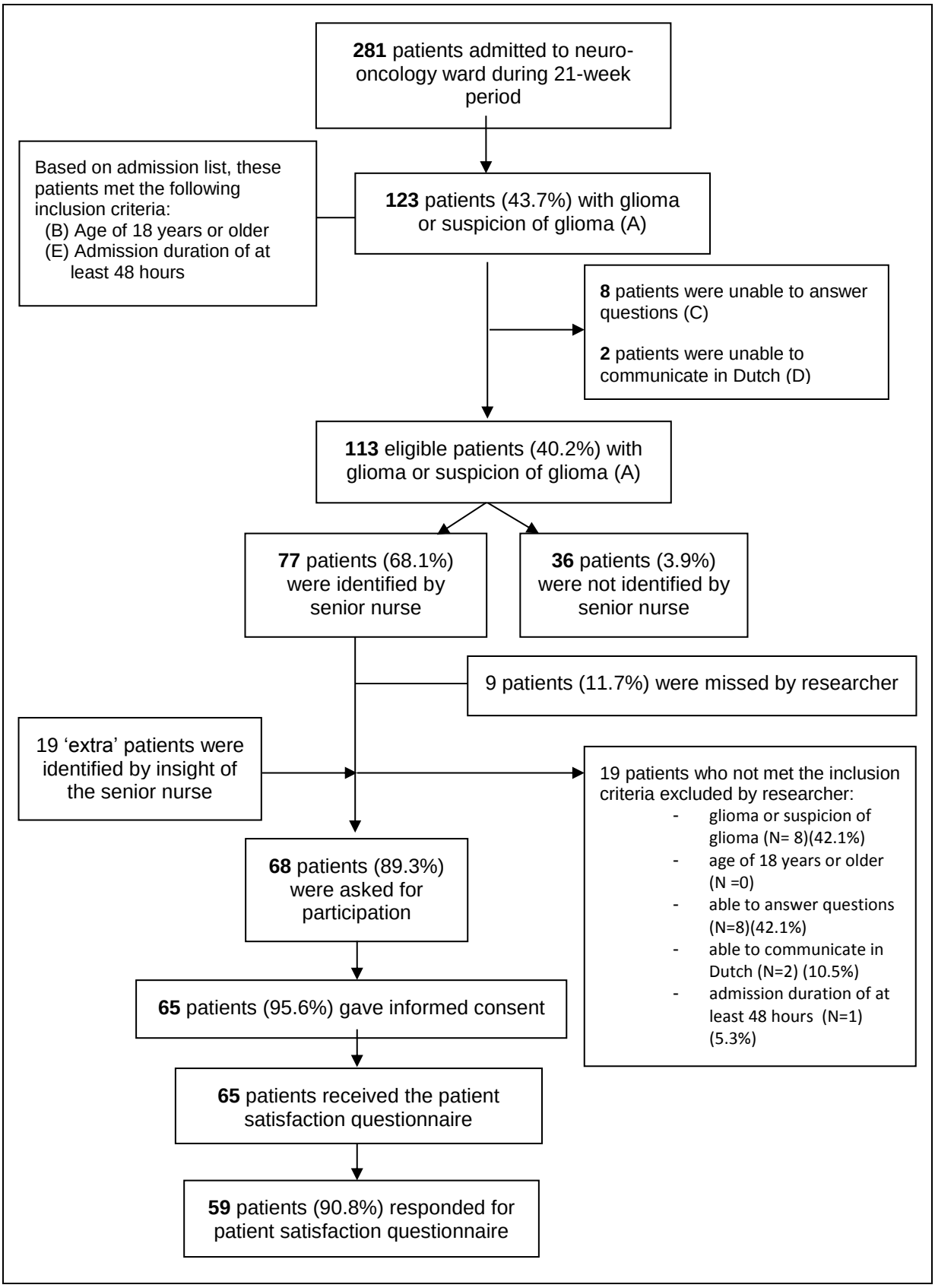

Figure 3 Flowchart recruitment procedures

Table 2 Patient satisfaction in SMP

Question	Mean (pretest)*	Mean (posttest)*	P-value
1. The attention for assessment of your symptoms and side effects by doctors and nurses?	4,35	4,44	0,889
2. The speed of assessment of your symptoms and side effects?	4,00	4,36	0,180
3. Referrals to experts when difficulties in treating symptoms or side effects? (For example: specialized doctors or nurses, physical therapy, psychologist)?	3,89	4,38	0,112
4. Given information about symptoms and side effects?	4,04	4,08	0,731
5. The extent to which you are involved in the decisions made about the treatment of your symptoms and side effects?	4,17	4,29	0,438
6. The extent to which your relative is (potentially) involved in the treatment of your symptoms and side effects?	4,07	4,64	0,005
7. The extent of evaluation if treatment of your symptoms and side effects actually helps?	3,87	4,38	0,048
8. The nurse's expertise regarding your symptoms and side effects?	4,14	4,58	0,017
9. Doctors' expertise regarding care for your symptoms and side effects?	4,39	4,38	1,000
10. The extent to which your various healthcare providers are aware of the treatment of your symptoms and side effects by interdisciplinary consultation?	4,15	4,17	0,958
11. The attention for complaints of distress?	4,27	4,27	1,000
12. The attention for epileptic seizures?	4,08	4,23	0,748
13. The attention for concentration and memory complaints?	3,92	4,10	0,445

*1: very dissatisfied, 2: dissatisfied, 3: satisfied nor dissatisfied, 4: satisfied, 5: very satisfied.

Appendix A - USD glioma

Utrecht Symptoom Dagboek (USD)

Versie Gliomen

UMC Utrecht
Cancer Center

Instructie
Door het dagelijks invullen van klachten en/of problemen die u ervaart kunnen we samen de passende zorg vaststellen, evalueren en waar nodig bijstellen.

Wilt u omcirkelen welk cijfer past bij hoe u de klachten en/of problemen ervaart op het moment van invullen?

We vragen ook naar uw kwaliteit van leven door de vraag over 'welbevinden'.

patiëntsticker

Datum _____

Ik heb op dit moment:												
geen pijn	0	1	2	3	4	5	6	7	8	9	10	erg veel pijn
geen slaapprobleem	0	1	2	3	4	5	6	7	8	9	10	erg groot slaapprobleem
geen droge mond	0	1	2	3	4	5	6	7	8	9	10	erg droge mond
geen slikklachten	0	1	2	3	4	5	6	7	8	9	10	erg veel slikklachten
goede eetlust	0	1	2	3	4	5	6	7	8	9	10	geen eetlust
normaal ontlastingspatroon	0	1	2	3	4	5	6	7	8	9	10	erg verstoord ontlastingspatroon
geen hoofdpijn	0	1	2	3	4	5	6	7	8	9	10	erg veel hoofdpijn
geen bewegingsprobleem	0	1	2	3	4	5	6	7	8	9	10	erg groot bewegingsprobleem
geen problemen met concentratie en geheugen	0	1	2	3	4	5	6	7	8	9	10	erg veel problemen met concentratie en geheugen
geen problemen met praten	0	1	2	3	4	5	6	7	8	9	10	erg veel problemen met praten
geen last van prikkelbaarheid/"kort lontje"	0	1	2	3	4	5	6	7	8	9	10	erg veel last van prikkelbaarheid/"kort lontje"
geen ongewild urineverlies	0	1	2	3	4	5	6	7	8	9	10	erg veel ongewild urineverlies
Ik voel me op dit moment:												
niet misselijk	0	1	2	3	4	5	6	7	8	9	10	erg misselijk
niet benauwd	0	1	2	3	4	5	6	7	8	9	10	erg benauwd
niet moe	0	1	2	3	4	5	6	7	8	9	10	erg moe
niet angstig	0	1	2	3	4	5	6	7	8	9	10	erg angstig
niet somber	0	1	2	3	4	5	6	7	8	9	10	erg somber
Anders												
_____	0	1	2	3	4	5	6	7	8	9	10	_____
Ik had de afgelopen 24 uur:												
geen epileptische aanvallen	0	1	2	3	4	5	6	7	8	9	10	erg veel epileptische aanvallen
Ik voel me op dit moment:												
goed	0	1	2	3	4	5	6	7	8	9	10	erg slecht

Welke klachten en/of problemen moeten wat u betreft als eerste aandacht krijgen?

_____

Appendix B - SMP Checklist

Symptom Management Performance checklist

A. Early signaling of symptoms
- attention to physical, psychological, social and spiritual dimension (of symptoms)
- use of measurement tools
- speed of signaling / period to signaling / detection by healthcare workers.

B. Tailored delivery of care to the (needs of the) patient, shared decision making
- patient involvement in decisions in (prioritization of) symptoms
- adapt symptom care to the needs of the patient

C. Treatment of symptoms in the multidisciplinary team
- expertise of the team
- setting goals
- intervention based on guidelines
- use of appropriate interventions
- (good) patient education about symptoms
- anticipating approach

D. Collaborate with relatives/loved ones and involvement of relatives/loved ones
- involving of relatives/loved ones in care decisions and participation in care
- education of relatives/loved ones.

E. Monitoring of symptoms
- reporting
- use of measurement instruments

F. Evaluation of symptom treatment in the multidisciplinary team
- evaluation of the effect of symptom treatment
- if necessary, adjustment of the intervention

G. Collaboration in the multidisciplinary team
- discussion of symptoms in multidisciplinary consultation meetings
- reporting on symptoms in transfer documents
- coordination and division of responsibilities of treatment and evaluation in the team

Appendix C – patients' comments on the SMP patient satisfaction questionnaire

Part one – procedural comments

Procedural comments	
Question 14: Are there any questions in this questionnaire that you found unclear or difficult to answer? If so, which questions and why?	Additional/general procedural comments
Question 12 + 13: Not unclear, but I have no complaints. Epilepsy – concentration – memory, hence (unknown). *[patient, code 63]* Question 7: patient experienced difficulty understanding. [*researcher, code 67*] Question 11 + 12: unknown questions, because she does not have experience with this *[researcher, code 73]* Question 5 + 6: Yes, question 5 and 6 difficult to read, in many questions 'the extent', patient was wandered by this. *[researcher, code 81]* Question 13: Hard to estimate, does not know how people work here. *[researcher, code 100]* In general: Mr. says when you explain it, it is clear [researcher, code 101] Ask more about grades 1-5 *[partner, code 101]*	POSTTEST PERIOD Question 11 +12: N / A *[patient, code10]* Question 8: N / A *[patient, code18]* Missing the option N / A *[researcher, Code18]* *Question 12: N / A [patient, code 25]* Question 11: not applicable *[researcher, code 34]* Mrs. was unable to remember what had happened during the admission. *[researcher, code 40]* *Question 12: N / A [patient, code 36]* PRETEST PERIOD Cognitively, the patient did not fully understand everything that happened on the ward. *[researcher, code 67]* I have no symptoms or side effects, so the whole thing is N / A. *[patient, code 70]* Question 12 + 13: N / A *[patient, code 86]* List was filled in together with sister, Mrs. forgets things *[researcher, code 90]* *Question 12: It doesn't bother me. [patient, code 91]* Mrs. has been a nurse herself. *[researcher, code 94]* Question 11 + 12: Mrs. isn't bothered by it. *[researcher, code 94]* Question 11: Dreariness has been filled in several times, filled in with '0', so extra

	attention is not needed in my opinion. *[patient, code 99]* Question 12: Idem is valid for epilepsy, filled in several times and indicated that I did not suffer from it, so extra attention is not needed. *[Patient, code 99]*

Part two – care-related comments

The questions are listed under the headings where they are given or noted by the patient. If comments are colored gray, they are copied and assigned to another heading by the researchers.

Care-related comments	
Pretest period	*Posttest period*
General comments	General comments
Very varied level of knowledge per nurse *[researcher, code 4]* Patient & loved-one indicate to have had a good experience, first experience / admission was very different. Didn't have the feeling to be heard back then, inexperienced staff, was a chaos. Very satisfied now. *[researcher, code 14]* Involve contribution of the neuropsychologist X in research *[researcher, code 15]* If: also miss: asked: do you have tips how to cook safely, no good answer, think there's more, more tips. *[researcher, Code 18]* Daughter goes to HDI but before we found out .... Purpose: Get tools with how to deal with it → Because you do not dare to ask for help in your surroundings. *[researcher, code 18]* Other note: heard that surgery was canceled, but without alternative *[researcher, code 24]* Patient: satisfied about department. However, not pleased with the approach of one doctor in treatment team (own doctor). He acts like a jerk. Speak to colleagues in an annoying way, talking very blunt about other patients on the phone. Doesn't stimulate confidence. *[researcher, code 26]*	Known in healthcare, worked as a nurse in psychiatry. *[researcher, code 68]* Due to the Easter weekend, referrals did not take place. *[researcher, code 77]* Mostly assistants have lack of knowledge *[researcher, code 77]* Mr. sometimes has the feeling that he needs to do things he does not want or that do not make sense. Mr. has not seen a doctor since surgery, this has been a discussion a number of times but no measures were taken. *[researcher, code 79]* Even student nurses were closely monitored. *[researcher, code 82]* Little monitoring of wound, that was a little strange. *[researcher, code 82]* If there is good communication within the team and with the patient, then that should be consistent, otherwise much work is for nothing. Repair is always more difficult than right the first time. *[patient, code 86]* Mr. is very satisfied. *[researcher, code 91]* Mrs. has been a nurse herself. *[researcher, code 94]*

	Hospitality is great. *[researcher, code 101]*
Question 1	Question1
Generally, very satisfied, except for one exception. Patient only once did not get enough rescues, nurse continued to claim that it should be correct. Had to convince the nurse of pain. Did not feel taken seriously. "A single nurse needs more education or does not like his job". *[researcher, code 17]* Very bad experience in Hospital X. *[researcher, code 18]* Nurses ask about pain regularly *[researcher, code 24]* Due to my chaotic condition + difficulty speaking there was no attention for choosing food, etc. Therefore, no good food + even more nauseous. Can't solve it myself. *[researcher, code 31]* Ocular complaints was not paid attention to at all = priority on USD! I once thought, I'm lying here ... at a neighbor, an ophthalmologist came by. *[researcher, code 34]* The care is good here. *[researcher, code 40]*	Also for partner very satisfied. *[researcher, code 71]* Little monitoring of wound, that was a little strange. [*researcher, code 82]* Compared to last time, attention was less alert and quick *[researcher, code 83]*
Question 2	Question 2
Partner indicates to be very dissatisfied. *[researcher, code 6]* Partner: Admission took too long because complaints she indicated about patient (especially irritability) were not seen as reason for medical admission *[researcher, code 6]* Exception *[researcher, code 17]* In general, very satisfied, except for one exception. Patient only once did not get enough rescues, nurse continued to claim that it should be correct. Had to convince the nurse of pain. Did not feel taken seriously. "A single nurse needs more education or does not like his job". *[researcher, code 17]* Staying here for a week now, came in with complaints, MRI made, do not really know	Not fast enough *[researcher, code 67]* Compared to last time, attention was less alert and quick *[researcher, code 83]*

yet. *[researcher, code18]* Because of my chaotic state, things are on hold for long. *[researcher, code 31]* Ocular complaints was not paid attention to at all = priority on USD! I once thought, I'm lying here ... at a neighbor, an ophthalmologist came by. *[researcher, code 34]*	
Question 3	Question 3
I'm not aware. *[researcher, code 18]* You don't get info OVU, could use more attention to people leaving the door, there is some room there. You must encourage people to step up, which opportunities are there. *[researcher, code 24]* Can also blame myself: asked little attention, but I could have used some more guidance, often walking around confused by myself. *[researcher, code 31]* Ocular complaints was not paid attention to at all = priority on USD! I once thought, I'm lying here ... at a neighbor, an ophthalmologist came by. *[researcher, code 34]*	Sometimes it takes a long time, but it's good though*. [researcher, code 71]* Due to the Easter weekend, referrals did not take place. *[researcher, code 77]* Difficulty with walking today, immediately on the same day the physiotherapy was enabled. *[researcher, 104]*
Question 4	Question 4
Variable per doctor, one better information/ approach than another *[researcher, code15]* Here I do see the leaflets but not in the 3 yrs before. Not offered *[researcher, code 18]* Had PID on admission day but it is too late, man has not read yet, should be sooner *[researcher, code 18]* I found the way myself. *[researcher, code 24]*	They give complete transparency. *[researcher, code 64]* Much in direction man *[researcher, code 67]* Sometimes it takes a long time, but good though*. [researcher, code 71]* Too little, due reduced insight into the disease, patient indicates that it goes well. But that's not true, thereby not enough information. *[researcher, code 100]*
Question 5	Question 5
Partner: it's not okay that when she asked the nurse something (info?), she indicated that she had to give patient permission. Expertise of nurses varies *[researcher, code 6]*	Notice to get less involved, people think I can do less, going through my boyfriend; I experience this as a failure. *[researcher, code 5]*

Nurses regularly ask about pain *[researcher, code 24]*	
Question 6	Question 6
	Ideal is the specialist nurse, she is nicely in the middle. Nurses let partner correctly say what the patient cannot say, they are taken seriously as a duo. *[researcher, code 101]*
Question 7	Question 7
Desired: also better reports + feedback to partner as well. Had to ask myself *[researcher, code 6]*	They were always asking about it *[researcher, code 64]*
Question 8	Question 8
Very varied level of knowledge per nurse *[researcher, code 4]* Partner: it's not okay that when she asked the nurse something (info?), she indicated that she had to give patient permission. Expertise of nurses varies *[researcher, code 6]* Partner: Expertise varies within nurses. Have to find out in dossier what has happened. Desired: Also report better + feedback to partner as well. Have to ask myself *[researcher, code 6]* Varies per nurse *[researcher, code 7]* In general, very satisfied, except for one exception. Patient only once did not get enough rescues, nurse continued to claim that it should be correct. Had to convince the nurse of pain. Did not feel taken seriously. "A single nurse needs more education or does not like his job". *[researcher, code 17]*	Even student nurses were closely monitored. *[researcher, code 82]* Little monitoring of wound, that was a little strange. *[researcher, code 82]*
Question 9	Question 9
About Professor X do not know *[patient, code 10]* Varies per doctor, one better information/ approach than another *[researcher, code15]* Patient: satisfied about department. However, not pleased with the approach of one doctor in treatment team (own doctor).	Talked about it more with nurse *[researcher, code 64]* Mostly assistants have lack of knowledge *[researcher, code 77]* Depends on physician + as layman it's difficult to estimate *[researcher, code 101]*

He acts like a jerk. Speak to colleagues in an annoying way, talking very blunt about other patients on the phone. Doesn't stimulate confidence. *[researcher, code 26]*	Mr. has not seen a doctor since surgery, this has been a discussion a number of times but no measures were taken. *[researcher, code 79]*
Question 10	Question 10
They work with team, I have confidence. *[researcher, code 24]* Responding to file. *[researcher, code 46]* If necessary, they do that. *[researcher, code 46]* Everyone knows what it's all about, I notice that. *[researcher, 54]*	If there is good communication within the team and with the patient, then that should be consistent, otherwise much work is for nothing. Repair is always more difficult than right the first time. *[patient, code 86]* This ward is more patient-friendly/ expert than surgical ward, not oncological ward, Read well here. *[researcher, code 101]*
Question 11	Question 11
Patient: when I was just admitted, I was very gloomy, not paid attention to it, also not indicated myself. Partner: Medical side more exposed than psychological memory problems, also makes it difficult. *[researcher, code 7]* They don't jump until it is actually too late. Other people are good for that, good if people can get support in that, some more attention would be good. Often, first patient sunk deeply. Now you hear through others, info HDI would be good. Do you stumble across it *[researcher, code 24]* I keep it to myself *[researcher, code 54]* Regarding fear / gloom: nobody knows about my situation, about my wife with ALS. *[researcher, code 54]*	They kept asking about it, was depressed earlier, by filling in USD. *[researcher, code 64]* Here better than on non-oncological surgical ward *[researcher, code 101]*
Question 12	Question 12
Too little attention for. *[researcher, code 18]* I keep it to myself *[researcher, code 54]*	Accidentally today *[patient, code 75]*
Question 13	Question 13
Asking for day and month everyday, patient had experienced as annoying + bring more variety in questions. → after 3 days a set pattern. [researcher, code 7]	

Didn't talk about it, would like tips, neuro-nurse more in the front. I miss the assistance; I miss that also in rehabilitation center. Would be nice if you can scan → suffer from this here, assistance how to handle. *[researcher, code 18]* Immediate attention for *[researcher, code 24]* Partner: no attention spent on - previous times more, patient: also no reason for. *[researcher, code 26]* I keep it to myself (patient calls wariness and concentration (memory)) as a priority on USD). *[researcher, code 54]*	