The ambulant status of patients with spinal bone metastasis in the pre- and post-surgery phase: a pilot study.

Masterthesis

Physiotherapy Science

Program in Clinical Health Sciences

Utrecht University

Name student:	S.A.J. (Suze) Toonders
Student number:	4188209
Date:	July 1, 2016
Internship supervisor(s):	Prof. Dr. C. (Cindy) Veenhof, Dr. J.J.(Jorrit-Jan) Verlaan
Internship institute:	Department of Rehabilitation, Nursing Science & Sport, University Medical Center Utrecht, Brain Center Rudolf Magnus Utrecht, Utrecht, The Netherlands.
Lecturer/supervisor Utrecht University:	Dr. M.F. (Martijn) Pisters

"ONDERGETEKENDE

Suze Adriana Johanna Toonders,

bevestigt hierbij dat de onderhavige verhandeling mag worden geraadpleegd en vrij mag worden gefotokopieerd. Bij het citeren moet steeds de titel en de auteur van de verhandeling worden vermeld."

Examiner

Dr. M.F. Pisters

Assessors:

Prof. Dr. C. Veenhof

Dr. J. van der Net

Masterthesis, Physical Therapy Sciences, Program in Clinical Health Sciences, Utrecht University, Utrecht, 2016

SAMENVATTING

Doelstelling: De keuze om patiënten met spinale botmetastasen in hun laatste levensfase chirurgisch te behandelen wordt ondersteund door medische scoringsystemen. Doelen van deze patiënten zijn hier niet in opgenomen en zijn meer gericht op het hervinden van zelfstandige mobiliteit en het vermogen zelfstandig te lopen. Daarnaast is de fysiotherapeutische zorg die deze patiënten ontvangen om deze doelen te realiseren niet helder. Het doel van deze pilotstudie is meer te weten komen over de functionele status van patiënten voor en na een operatie, inzicht krijgen in de belangrijkste doelen die patiënten zichzelf stellen en de verwezenlijking daarvan, achterhalen wat voor soort fysiotherapiebehandeling deze patiënten ontvangen en of preoperatieve fysiotherapie haalbaar is.

Methode: Deze observationele pilot cohortstudie werd verricht op de afdeling orthopedie in het Universitair Medisch Centrum Utrecht, Nederland. Er werd een convergent mixed method studie uitgevoerd. Kwantitatieve gegevens bestonden uit scores op Tokuhashi, Tomita en de Karnofsky Performance Score, de Numeric Rating Scale en EuroQol-5D vragenlijst, zowel preoperatief als drie maanden postoperatief. Verdiepende kwalitatieve gegevens werden zowel preoperatief (patiënt specifieke klachten) als zes weken na de operatie (semigestructureerde interviews) verzameld.

Resultaten: Kwantitatieve gegevens kwamen uit een bestaande dataset van 51 patiënten. De functionele status verbeterde significant na de operatie, evenals pijn, mobiliteit, zelfzorg en de uitvoering van dagelijkse activiteiten. Bij zes patiënten werden kwalitatieve gegevens verzameld. De doelstellingen en verwachtingen van patiënten bleken te liggen op het niveau van het verbeteren van het vermogen dagelijkse activiteiten uit te voeren. Fysiotherapie na ontslag verschilde per persoon en er bleek om verschillende redenen geen mogelijkheid te zijn voor preoperatieve training.

Conclusie: De doelen van patiënten met spinale botmetastasen verschillen van de huidige standaard medische scoringsystemen. Preoperatieve fysiotherapie is alleen haalbaar als patiënten in een eerder stadium worden verwezen naar de orthopedisch chirurg. Verwijzing voor fysiotherapie na ontslag moet worden geoptimaliseerd, omdat dit kan faciliteren dat patiënten de doelen behalen die zij zich voorafgaand aan de operatie stellen.

Klinische relevantie: Het verwijsbeleid richting de orthopedisch chirurg in de preoperatieve fase en de fysiotherapeut in de postoperatieve fase kan leiden tot een betere haalbaarheid van doelen die patiënten met spinale botmetastasen zich stellen.

ABSTRACT

Aim: The decision to surgically treat patients with spinal bone metastases at the end-stage of their life is supported by medical scoring systems. Personal goals of patients are not included in these scoring systems and are rather based on independent mobility and ambulatory status. It is furthermore not clear what kind of physical therapy patients receive to achieve these goals. The aim of this pilot study is to better understand the functional status of patients before and after surgery, understand patients' main goals and whether they achieve them, and gain insight into the type of physical therapy patients receive in addition to surgery and whether preoperative physical therapy is achievable.

Methods: This observational pilot cohort study was performed at the orthopedic department of the University Medical Centre Utrecht, the Netherlands. A convergent mixed method study was used. Quantitative data consisted of the Tokuhashi, Tomita and the Karnofsky Performance Score, the Numeric Rating Scale and EuroQol-5D questionnaire, both preoperative and three months after surgery. Additional qualitative data were both collected preoperatively (Patient Specific Questionnaire) as well as six weeks after surgery (semi-structured interviews).

Results: Quantitative data were taken from an existing dataset covering 51 patients. Patients' functional status improved significantly after surgery, as did their pain level, mobility, self-care and ability to perform daily activities. Qualitative data were collected from six patients. The goals and expectations of patients were improving the ability to perform daily activities. Physical therapy practices after discharge differed by patient. For various reasons there was no possibility for preoperative training.

Conclusion: The goals of patients with spinal bone metastases differ from current standard medical scoring systems. Preoperative physical therapy is only achievable if patients are referred to an orthopedic surgeon at an earlier stage. Referral to physical therapy after discharge has to be optimized in order to facilitate patients in meeting the goals they set themselves prior to surgery.

Clinical relevance: The referral policy to the orthopedic surgeon in the preoperative phase and to the physical therapist in the postoperative phase can improve the feasibility of meeting goals patients with spinal metastases set themselves prior to surgery.

Keywords: spinal bone metastasis, physical therapy specialty, palliative care, patient preference

INTRODUCTION

In 2013, the overall incidence of all types of cancer was 606 per 100,000 persons per year in the Netherlands(1). Bone metastases develop in about ten percent of all patients with cancer(2), with the spine as the most common location(3). Although it is unknown why some types of cancer metastasize to the bone(4), metastasization is most likely in the case of breast, prostate, lung, thyroid and kidney tumors(5,6). Bone metastases can result in bone fragility and the development of new cells(7)(8). Patients are affected by pain, spine instability and neurologic deficits or other problems that limit the ability to perform daily activities(9). The mean survival time of patients with a bone metastasis depends on the primary tumor site and pre ambulatory status(10–12), defined as the ability to walk(10,11), and ranges from three to eighteen months(6). The highest survival times are found among patients with a primary tumor in breast, prostate or thyroid(5,6) and patients who are ambulant before surgery(10,11).

Medical interventions focus on pain control and preservation of physical functioning(5), and are often palliative or supportive(13). The main treatment options for spine metastases are radiation therapy and surgery(14). Surgery is associated with pain relief, improved quality of life and an improvement in the ability to perform daily activities(9). Surgery does not extend the duration of life, but can shrink the metastasis, and stop or slow its growth(5,15). The choice to apply surgery can be supported by medical scoring systems, such as the Tomita scoring system(16) and Tokuhashi score(17). Indications for surgery are: a) a progressive neurologic deficit before, during or after radiation therapy, b) intractable pain unresponsive to conservative treatment, c) radio-resistant tumor histology d) spinal instability and e) a survival time of ≥3 months(6,9,18). Disease acceptance and expectations of the future differ among patients in the palliative phase(19). It is recommended to take patients' preferences and expectations into account when deciding for surgery(20–23). Among patients with cancer in general, there is a strong desire for independent mobility, even in the last three days of life(24). Among patients with spinal metastases, prior to surgery goals are centered around the ability to perform daily activities and ambulatory status(21).

Physical therapy can support patients in reaching goals they hope to achieve with surgery. Physical therapy is recommended as usual care(24,25) for patients with spinal bone metastases after hospital discharge to support independent mobility, the ability to perform daily activities, mood and quality of life(26–29). Physical therapy has been found to be safe and effective(19,24,25,30). Besides postoperative physical therapy, preoperative physical therapy can improve the ambulatory status prior to surgery for patients with cancer in general(29). To date, preoperative physical therapy is not offered as standard usual care for patients with spinal bone metastases.

This pilot study evaluates patients who underwent surgery for bone metastasis to (1) better understand their functional status before and after surgery; (2) gain insight in the main goals of these patients prior to surgery; (3) understand whether they achieve these goals; (4) gain insight into the physical therapy these patients receive before and after surgery.

METHODS

Design and Setting

This descriptive, observational study was performed at the orthopedic department of the University Medical Center Utrecht (UMC Utrecht), the Netherlands. To report transparently about this study, the checklist for pilot studies adopted from the CONSORT statement(31) was used. Since both quantitative and qualitative data were needed to achieve the aims of this pilot study, a convergent mixed method design was used(32). The quantitative data was used for the first aim, namely achieving a better understanding of patients' functional status before and after surgery, by describing physical variables such as functional status and pain and health levels. Additional qualitative data were used to achieve the second, third and fourth aim of this study. The quantitative data were collected for and during usual care. For the qualitative data, a proposal for a non-WMO study was approved by the METC committee of the University Medical Center Utrecht (15-635/C).

Quantitative sample

The quantitative data consisted of a convenience sample of 51 patients who had undergone spinal bone surgery in 2015 in the UMC Utrecht.

Quantitative data

The quantitative data consisted of demographic data, outcomes of a scoring system and questionnaires and were obtained preoperatively and three months after surgery. Demographic data were obtained from medical files and contained information on age, length of stay in hospital, gender and tumor site. The Tokuhashi score measured six items on general condition, number of extra spinal bone metastases, the number of metastases in the vertebral body, metastases to the major internal organs, the primary site of cancer and the severity of spinal cord palsy(33). The maximum score was 15 and scores between 0-8, 9-11, and 12-15 predicted a life expectancy of less than six months, six months or more, and one year or more, respectively(33). A study following 246 patients with spinal bone metastases found an agreement between predicted and actual survival time in 82,5% of cases(17). The Tomita scoring system consisted of three prognostic factors: the rate of growth of the primary tumor, number of bone metastases and visceral metastases(16). The surgeon scored items on a scale from 2-10 and determined the treatment goal and surgical strategy. The expected survival time was more than two years if the total score was between 2-4, one to two years if the total score was 4-6, six months to one year if the total score was 6-8 and less than three months if the total score was between 8-10(33). The Tomita score has been found to be useful for predictions of long-term survival(34). The Frankel score measured whether a neurological deficit was neurologically complete or incomplete(35). The surgeon classified patients neurologically ranging between A: 'Complete', B: 'Sensory incomplete', C: 'Motor incomplete', D: 'Motor incomplete' and E: 'Normal'. Validation or reliability of this international standard for neurologic classification was not available.

Other quantitative data consisted of a scoring system and questionnaires. The Karnofsky Performance Scale (KPS) quantified patients' functional status(36), defined as the level of physical or motor skills or activities in everyday activities(37). The percentage scores of the KPS described the conditions A: 'Able to carry on normal activity and work' (100–80%), B: 'Unable to work; able to live at home and care for most personal needs' (70–50%) and C: 'Unable to care for self; requires equivalent of institutional hospital care, diseases may by progressing rapidly' (40–0%). The KPS has been found valid and reliable in patients with cancer(38). The Numerical Rating Scale (NRS) was used to measure the experienced pain, has been found to be the most clinically relevant measure for chronic cancer pain assessment, aside from being valid and reliable(39). The NRS ranged from zero (no pain) to ten (worst pain imaginable). The clinically relevant difference for chronic pain patients have been found to be more than 30 percent(40,41). Quality of life was measured by the EuroQol-5D (EQ-5D), an international standardized instrument to measure health status(42). The instrument included the amount of problems (low, moderate or many) on five health levels: mobility, self-care, usual activities, pain and anxiety and depression(43). The instrument was developed to evaluate the impact of medical interventions over time. Minimal important changes have been based on aggregated statistics of these five health levels(42), but not on each health level separately.

Qualitative sample

The qualitative data was formed by a convenience sample. To be eligible to participate, a subject had to meet the following criteria: a) oncology patient ≥ 18 years at UMC Utrecht and b) have a bone metastasis in the spinal region with a surgical indication between February 1, 2016 and April 15, 2016. If a potential subject had an inadequate understanding of the Dutch language, the subject was excluded.

Qualitative data

In-depth qualitative data were collected preoperatively through a Patient Specific Questionnaire (PSK) and postoperatively through a semi-structured interview six weeks after surgery. The outcome of the PSK was combined with answers given in the semi-structured interviews. A physical therapist who worked at the UMC Utrecht obtained scores on the PSK, while the researcher held semi structured interviews. In the PSK, patients gave the three most important problems facing them during daily activities and indicated the most important goals after surgery. The instrument has been found valid and reliable for different patient groups(44). Questions during the semi-structured interviews were aimed at describing the goals and expectations of patients(45), more specifically, understanding patients' experienced loss of mobility during the hospital stay, physiotherapeutic care and ways in which patients were supported to regain independent mobility (see Appendix 1).

Data Analysis

The quantitative data were analyzed using SPSS 23®. KPS and NRS were analyzed in a Generalized Linear Mixed Model (GLMM). KPS was used as a continuous outcome variable, as common to the literature(46). GLMM analysis treated time as a fixed factor and patient as a random factor. The Wilcoxon Signed Rank Test was used to determine change in health levels from EQ-5D.

Qualitative data were analyzed using QRS NVIVO 10®. Interview audiotapes were transcribed, as was the outcome of the PSK. Axial and selective coding was performed by the researcher to form themes and categories.

RESULTS

Patient Characteristics

The quantitative dataset consisted of 51 patients (25 male and 26 female) receiving surgery for spinal bone metastasis. Patients on average were middle aged (64.9 ±10.7 years), had a life expectancy of more than six months (Tokuhashi Score 9 ± 3.14 points), had a hospital length of stay of almost two weeks (13.4 ±16 days) and had different tumor sites as well as different Tomita scores. Forty-five patients (88%) scored a D or E on the Frankel score, implying at least preserved neurologic or normal motor function. Twenty-seven patients (53%) were followed up after three months. Half of patients lost to follow up deceased within three months after surgery (Table 1). Patients that remained in follow up were comparable to the baseline scores of all patients concerning their age, gender, length of stay in hospital and Tokuhashi score, while sites of the tumor site and Tomita Scores differed between baseline and follow up (Table 2).

Table 1: Loss to follow up after three months

Reason for loss to follow up	**N (%)**
Deceased	12 (50)
Further treatment in other hospital	3 (13)
Further treatment in nursing home	2 (8)
Further treatment in rehabilitation center	1 (4)
Unknown*	6 (25)

* Unknown, not reported. *Average Tokuhashi Score for this subgroup: 11. Tumor sites: breast, unknown, myeloma and prostate. Tomita Score ranges between 1-2.*

The qualitative sample consisted of six patients. Within the inclusion period of two and a half months ten patients underwent spinal bone surgery. Four patients were seen by another surgeon and could not be included. None of the patients were excluded because of an inadequate understanding of the Dutch language. The PSK was completed by three patients (three patients were missed by the physical therapist) and the semi-structured interviews were held with four patients (one patient refused and one patient did not show up at the appointment because of poor prognosis). Although gender and length of stay in hospital of

the qualitative sample differed from the quantitative sample, in all other respects the qualitative sample appeared representative.

Table 2: Patient characteristics

Variables	Quantitative sample Baseline (preoperative) N = 51	Quantitative sample Follow up (3 months) N = 27	Qualitative sample N = 6
Age, in years, mean (SD)	64.90 (10.65)	66.48 (11.0)	61.0 (11.14)
Tokuhashi Score, mean (SD)	9.06 (3.14)	9.30 (2.9)	8.2 (3.11)
Tokuhashi Survival Prognosis			
<6 months, N (%)	19 (37.3)	9 (33.3)	3 (50)
6-12 months, N (%)	23 (45.1)	14 (51.9)	1 (25)
>1 year, N (%)	9 (17.6)	4 (14.8)	1 (25)**
Length of stay in hospital, mean (SD)	13.44 (16.02)	13.2 (18.96)	6 (1.414)*
Gender, N (%)			
Male	25 (49)	13 (48)	1 (16.7)
Female	26 (51)	14 (52)	5 (83.3)
Tumor site, N (%)			
Breast	11 (21.6)	8 (30)	2 (40)
Lung	6 (11.8)	2 (7)	2 (40)
Myeloma	5 (9.8)	3 (11)	1 (20)
Renal	7 (13.7)	5 (19)	0 (0)
Unknown	5 (9.8)	2 (7)	0 (0)
Other	17 (33.3)	7 (26)	0 (0)**
Tomita Score, N (%)			
Expected survival time > 2 years	31 (60.8)	19 (70)	3 (50)
Expected survival time 1-2 years	2 (3.9)		
Expected survival time 6-12 months (Palliative surgery)	8 (15.7)	6 (22)	1 (16.7)
Expected survival time< 3 months (Supportive care)	10 (19.6)	2 (8)	2 (33.3)
Frankel score, N (%)			
A	0 (0)	0 (0)	0 (0)
B	1 (2)	0 (0)	0 (0)
C	5 (9.8)	0 (0)	0 (0)
D	13 (25.5)	4 (7.8)	2 (33.3)
E	32 (62.7)	23 (45.1)	3 (50)**

**Missing values for four patients. ** Missing value for one patient.*

Ability to function in daily life

The KPS on average significantly improved after three months (9.33, p=0.000) (Table 3). The KPS deteriorated among four patients (8%) after three months, while it improved among sixteen patients (31%) in the same period. The KPS of seven patients (14%) did not change. For the remaining 24 patients (47%) from the baseline, the follow up score is unknown. Dividing the KPS into three categories, each with its own likelihood of survival and ambulatory status, eight patients (16%) improved from category from B to A, while two patients (4%) improved

from category C to B (Figure 1). At follow up, all 27 patients belonged to categories A and B, implying they were able to live at home and care for most personal needs.

Pain

Pain on average decreased by 1.5 points in three months, from 4.5 to 3.0 (a decrease of 33.3%) on the NRS (p=0.003) (Table 3). This decrease was above the clinically relevant difference of thirty percent(40,41). The pain intensity score of five patients (10%) increased three months after surgery, while among 18 patients (35%) it decreased. Of these 18 patients, 13 (25%) met the clinically relevant difference. The score of four patients (8%) did not change. For the remaining 24 patients (47%) from the baseline, the follow up score is unknown. No significant difference was found (p=0.627) for the pain subscale measured by the EQ-5D.

Table 3: Clinical characteristics

	Baseline (preoperative) N = 51	**Follow up (3 months) N = 27**	**Difference (p-value)**
KPS, mean (SD)[1]	62.35 (1.89)	71.68 (2.18)	9.33 (0.000)
NRS, mean (SD) [1]	4.5 (0.45)	3.0 (0.37)	-1.51 (0.003)
	Baseline (preoperative)	**Follow up (3 months)**	**Test statistic (p-value)**
EQ-5D Mobility[2], N (%)			-3.343 (0.001)
Walking without problems	6 (12.2)	13 (48.1)	
Walking with some problems	20 (40.8)	12 (44.4)	
Bedbound	23 (46.9)	2 (7.4)	
Missing value	2	24	
EQ-5D Self-Care[2], N (%)			-2.696 (0.007)
Wash or dress myself without problems	6 (12.2)	12 (44.4)	
Wash or dress myself with some problems	29 (59.2)	13 (48.1)	
Unable to wash or dress myself	14 (28.6)	2 (7.4)	
Missing value	2	24	
EQ-5D Usual Activities[2], N (%)			-2.399 (0.016)
No problems with daily activities	1 (2.0)	5 (18.5)	
Some problems with daily activities	20 (40.8)	14 (51.9)	
Unable to carry out daily activities	28 (57.1)	8 (29.6)	
Missing value	2	24	
EQ-5D Pain[2], N (%)			-0.486 (0.627)
No pain	3 (6.1)	6 (22.2)	
Moderate pain	37 (75.5)	15 (55.6)	
Earnest pain	9 (18.4)	6 (22.2)	
Missing value	2	24	
EQ-5D Anxiety / Depression[2], N (%)			-1.000 (0.317)
No anxiety or depression	32 (65.3)	19 (70.4)	
Moderate anxiety or depression	16 (32.7)	8 (29.6)	
Extreme anxiety or depression	1 (2.0)	0 (0)	
Missing value	2	24	

[1] Based on GLMM [2] Based on Wilcoxon Signed Rank Test

Health levels

Beyond the pain subscale of the EQ-5D, positive significant differences are found in the subscales mobility (p=0.001), self-care (p=0.007) and usual activities (p=0.016). No significant difference was found in the subscale for anxiety or depression (p=0.317).

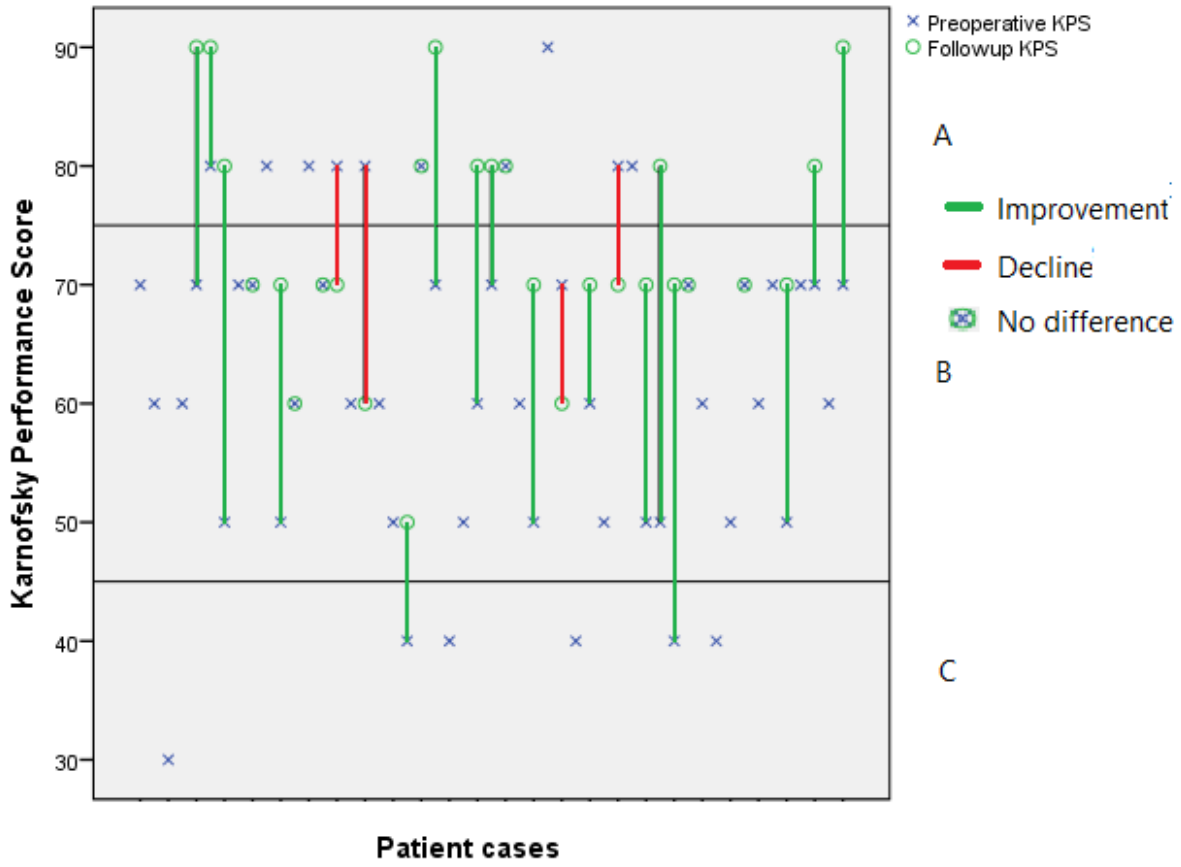

Figure 1: Change in Karnofsky Performance Score linked to categories A, B and C

Achievement of goals

The goals patients set prior to surgery, measured by the PSK, were focused on the ability to perform daily activities and ambulant status, e.g. "improving my condition to enter the radiation as fit as possible", "improve my walking ability and be able to shop with sister" or "become independent". From the PSK scores it appeared that six weeks after surgery patients were not as independent in their mobility as they expected. Patients indicated they could only walk short distances unassisted and needed a wheelchair for longer distances: "I still cannot climb stairs, and sit with a maximum of two hours", and "I can walk alone, although it becomes rough. I'll try, but I had really hoped to be more mobile". Patients (n=3) expected to be more mobile, while one person did not have much expectations from surgery, as there was no other option. The semi-structured interviews showed all patients (N=4) experienced a loss of mobility because of the admission.

The type of physical therapy care patients received after discharge

All patients reported they went home after clinical admission. The discharge decision was made by the patient or by orthopedist or surgeon, and not jointly: "I just wanted to go home and the doctors agreed", or the decision was made "by the doctors, I also wanted to get home". Patients were seen directly after the discharge by a physical therapist (n=3). One patient arranged this herself. Physical therapy was focused on mobilization, walking therapy, muscle strengthening exercises and giving advice: "Mobilization to walk properly, exercise therapy for muscle strengthening and advice about exercise capacity". The frequency of physical therapy ranged from once a week to daily therapy, and was home based in all cases.

Feasibility of preoperative physical therapy

Mobility before surgery ranged from independent walking (n=1) to not being able to move legs (n=2) or not being allowed to be active because of the risk of paraplegia (n=1). "I really had a lot of pain for ten months ... unbearable ... I was already on a crutch because I just wanted to do things on my own in order to preserve my independence, but at one point I was dependent on care. I could no longer use my left leg". All patients said they felt restricted in their daily activities by pain. Preoperative training was not possible for any of the patients, either because of the emergency of the surgery (within one week) (n=3) and because of restrictions on mobility because of the risk of paraplegia (n=1): "It was not possible due the spinal cord injury risk. Surgery was within two weeks ... I was not allowed to move because they were afraid. I had 90% chance of a spinal cord injury". Appendix 2 provides an overview of all interview statements.

DISCUSSION

Criteria for surgery are mainly based on life expectancy, number of (extra) metastases, primary tumor site, degree of neurological deficit and level of functional status(16,17,38). To date there is no criterion available that focuses on the main goals patients have, such as the ability to perform daily activities and ambulatory status. Literature highlights the importance of taking personal goals into account(22,23), particularly of patients in the end stages of life(19). Adding a questionnaire focusing on the physical activity level or including physical clinimetrics in the criteria for surgery would improve the understanding of patients' personal needs and expectations. On the basis of the interviews in this pilot study it appears that patients' goals were often not achieved. The interviews held six weeks after surgery however may have been held too soon to come to this conclusion.

Physical therapy can help patients reach their goals in regaining independent mobility and ambulatory status. Patients experienced the added value of physical therapy. Therapy given after discharge however is different between patients, ranging from therapy once a week to daily appointments, and started at different points in time after discharge. Physical therapy is part of usual care and every patient should be referred to a physical therapist, adapting the therapy to their personal goals(24,25). Preoperative training was not prescribed for or followed

by any patient as it did not seem achievable, given the urgency of surgery within two weeks in which physiological effects cannot be reached. Restricted mobility under paraplegia risk also was a reason why a patient could not train preoperatively. Preoperative physical therapy however can help patients improve their functional status prior to surgery, helping patients realize the goals they set for surgery. This therapy only is possible if patients are referred to the orthopedic surgeon more than two weeks before surgery. Future studies should focus on earlier referral and the assess the effectiveness of preoperative physical therapy on the attainment of the personal goals of patients.

The outcome of this pilot study confirms earlier outcomes of literature indicating that the functional status of patients changes significantly after surgery(18). Based on the KPS, it appears that all patients are able to live at home and care for their most personal needs themselves after surgery. A possible explanation for this change is the restriction in mobility before surgery (in case of paraplegia risk) which is relieved after surgery. Patients furthermore experience less neurologic problems and less pain after surgery, confirming earlier findings(9). Although attrition bias remains a concern, the average decrease in pain measured by the NRS was clinically relevant(39,40) over the period of three months in this pilot study in 25 percent of all patients. In the pain subscale of the EQ-5D, no significant decreases over time were found. The EQ-5D however measures pain on a three-point scale compared to the eleven-point scale of the NRS, implying it is less sensitive and therefore may underestimate changes in experienced pain(48).

Limitations

Interviews gave more insight into personal goals and expectations of this patient population. No new codes were formulated after the analysis of the fourth interview. Results of this small convenience sample are however difficult to generalize to the entire population. The demographic characteristics of the small sample however were similar to the larger and more representative baseline sample. The follow up quantitative data consisted of 27 patients, compared to 51 patients at the baseline. Reasons for loss to follow up give insight in potential attrition bias. Care is required in the interpretation of the differences between the baseline and follow up, as figures are likely upwardly biased given half of patients lost to follow up were deceased. Finally, the PSK questionnaires were only used as a qualitative tool to identify the main problems of patients. This way of using the PSK is not validated, but considering the small sample it was not possible to perform statistical analyses on the PSK.

Suggestions for future research

The results of this pilot study support the feasibility of a larger longitudinal study focusing on the ambulant status and the setting of personal goals of patients who undergo spinal bone surgery. Because of convenience sampling no power calculation was performed, yet in such a larger longitudinal study, sufficient power is necessary. Further research is needed to understand both whether patients achieve goals set prior to surgery, and whether these goals are realistic. Such a study could benefit from adding a questionnaire focused on physical

activity or adding physical clinimetrics to usual care. Future studies furthermore should try to understand the causes and effects of differences in referral practices to physical therapists after surgery, and study whether earlier referral to the orthopedic surgeon can give patients the opportunity to train before surgery, potentially helping patients reach their goals.

CONCLUSION

The functional status of patients measured with the KPS improves significantly after surgery, as does pain, mobility, self-care and the ability to perform daily activities. The goals of patients with spinal bone metastases differ from the current standard medical scoring systems and measurements as KPS, and focus rather on the ability to perform daily activities and ambulatory status. As most of the patients are in end stages of life, it is important to take this personal goals into account and assess whether patients reach these goals before and after surgery. To facilitate referral to preoperative physical therapy, patients should be referred to the orthopedic surgeon in an earlier stage. Although referral to physical therapy is already included in usual care(25), not all patients are referred to physical therapy, so the referral process needs to be optimized. Physical therapy can help patients reach their goals in regaining independent mobility and improve their ambulatory status.

REFERENCES

1. Integraal kankercentrum Nederland. Cijfers over kanker [Internet]. Cijfers over kanker. Available from: http://www.cijfersoverkanker.nl/p=56080c59ef5a9

2. Boogerd W, van der Sande JJ. Diagnosis and treatment of spinal cord compression in malignant disease. Cancer Treat Rev. 1993;19(2):129–150.

3. Maccauro G, Spinelli MS, Mauro S, Perisano C, Graci C, Rosa MA. Physiopathology of Spine Metastasis. International Journal of Surgical Oncology. 2011;2011:1-8.

4. Mundy GR. Metastasis: Metastasis to bone: causes, consequences and therapeutic opportunities. Nat Rev Cancer. 2002 Aug;2(8):584–93.

5. Bhatt AD, Schuler JC, Boakye M, Woo SY. Current and emerging concepts in non-invasive and minimally invasive management of spine metastasis. Elsevier. 2013;142–52.

6. Bartels RHMA, van der Linden YM, van der Graaf WTA. Spinal Extradural Metastasis: Review of Current Treatment Options. CA Cancer J Clin. 2008 Mar 19;58(4):245–59.

7. Nielsen OS, Munro AJ, Tannock IF. Bone metastases: pathophysiology and management policy. J Clin Oncol. 1991;9(3):509–524.

8. Roodman GD. Biology of osteoclast activation in cancer. J Clin Oncol. 2001;19(15):3562–3571.

9. Heary RF, Bono CM. Metastatic spinal tumors. Neurosurg Focus. 2001;11(6):1–9.

10. Kim CH, Chung CK, Jahng T-A, Kim HJ. Resumption of ambulatory status after surgery for nonambulatory patients with epidural spinal metastasis. Spine J. 2011;11(11):1015–1023.

11. Park JH, Jeon SR. Pre- and postoperative lower extremity motor power and ambulatory status of patients with spinal cord compression due to a metastatic spinal tumor. Spine. 2013 Jun 1;38(13):E798-802.

12. Conway R, Graham J, Kidd J, Levack P, others. What happens to people after malignant cord compression? Survival, function, quality of life, emotional well-being and place of care 1 month after diagnosis. Clin Oncol. 2007;19(1):56–62.

13. Selvaggi G, Scagliotti GV. Management of bone metastases in cancer: A review. Crit Rev Oncol Hematol. 2005 Dec;56(3):365–78.

14. Richtlijnwerkgroep Wervelmetastasen. Conceptrichtlijn Wervelmetastasen. Integraal Kankercentrum Nederland; 2014.

15. Onimus M, Papin P, Gangloff S. Results of surgical treatment of spinal thoracic and lumbar metastases. Eur Spine J. 1996;5(6):407–411.

16. Tomita K, Kawahara N, Kobayashi T, Yoshida A, Murakami H, Akamaru T. Surgical strategy for spinal metastases. Spine. 2001;26(3):298–306.

17. Tokuhashi Y, Matsuzaki H, Oda H, Oshima M, Ryu J. A revised scoring system for preoperative evaluation of metastatic spine tumor prognosis. Spine. 2005;30(19):2186–2191.

18. Patchell RA, Tibbs PA, Regine WFR, Payne R, Saris S, Kryscio RJ, et al. Direct decompressive surgical resection in the treatment of spinal cord compression caused by metastatic cancer: a randomised trial. The Lancet. 2005 Aug;643–8.

19. Cheville A. Rehabilitation of patients with advanced cancer. Cancer. 2001;92(S4):1039–1048.

20. Loblaw DA. Systematic Review of the Diagnosis and Management of Malignant Extradural Spinal Cord Compression: The Cancer Care Ontario Practice Guidelines Initiative's Neuro-Oncology Disease Site Group. J Clin Oncol. 2005 Feb 7;23(9):2028–37.

21. Abrahm JL, Banffy MB, Harris MB. Spinal cord compression in patients with advanced metastatic cancer:"all I care about is walking and living my life." JaMA. 2008;299(8):937–946.

22. Elkadry EA, Kenton KS, FitzGerald MP, Shott S, Brubaker L. Patient-selected goals: A new perspective on surgical outcome. Am J Obstet Gynecol. 2003 Dec;189(6):1551–7.

23. Flood AB, Lorence DP, Ding J, McPherson K, Black NA. The Role of Expectations in Patients' Reports of Post-Operative Outcomes and Improvement Following Therapy. Medical Care. 1993;31(11):1043–56.

24. Yoshioka H. Rehabilitation for the terminal cancer patient. American Journal of Physical Medicine & Rehabilitation. 1994;199–206.

25. Integraal kankercentrum Nederland. Oncoline [Internet]. Richtlijn oncologische zorg. 2011 [cited 2016 May 22]. Available from: http://www.oncoline.nl/oncologische-revalidatie

26. Raj VS, Lofton L. Rehabilitation and treatment of spinal cord tumors. J Spinal Cord Med. 2013 Jan;36(1):11–4.

27. Tang V, Harvey D, Dorsay JP, Jiang S, Rathbone MP. Prognostic indicators in metastatic spinal cord compression: using functional independence measure and Tokuhashi scale to optimize rehabilitation planning. Spinal Cord. 2007;45(10):671–677.

28. Ruff RL, Ruff SS, Wang X. Persistent benefits of rehabilitation on pain and life quality for nonambulatory patients with spinal epidural metastasis. J Rehabil Res Dev. 2007;44(2):271.

29. Silver JK, Baima J. Cancer Prehabilitation: An Opportunity to Decrease Treatment-Related Morbidity, Increase Cancer Treatment Options, and Improve Physical and Psychological Health Outcomes. Am J Phys Med Rehabil. 2013 Aug;92(8):715–27.

30. Bunting RW, Shea B. Bone metastasis and rehabilitation. Cancer. 2001;92(S4):1020–1028.

31. Thabane L, Ma J, Chu R, Cheng J, Ismaila A, Rios LP, et al. A tutorial on pilot studies: the what, why and how. BMC Med Res Methodol. 2010;10(1):1.

32. Klassen AC, Creswell J, Plano Clark VL, Smith KC, Meissner HI. Best practices in mixed methods for quality of life research. Qual Life Res. 2012 Apr;21(3):377–80.

33. Tokuhashi Y. Scoring system for prediction of metastatic spine tumor prognosis. World J Orthop. 2014;5(3):262.

34. Choi D, Morris S, Crockard A, Albert T, Bunger C, Fehlings M, et al. Assessment of Quality of Life After Surgery for Spinal Metastases: Position Statement of the Global Spine Tumour Study Group. World Neurosurg. 2013 Dec;80(6):e175–9.

35. Kirshblum SC, Burns SP, Biering-Sorensen F, Donovan W, Graves DE, Jha A, et al. International standards for neurological classification of spinal cord injury (Revised 2011). J Spinal Cord Med. 2011 Nov;34(6):535–46.

36. Péus D, Newcomb N, Hofer S. Appraisal of the Karnofsky Performance Status and proposal of a simple algorithmic system for its evaluation. BMC Med Inform Decis Mak. 2013;13(1):72.

37. Sørensen JB, Klee M, Palshof T, Hansen HH. Performance status assessment in cancer patients. An inter-observer variability study. Br J Cancer. 1993;67(4):773.

38. Mor V, Laliberte L, Morris JN, Wiemann M. The Karnofsky performance status scale: An examination of its reliability and validity in a research setting. Cancer. 1984;53(9):2002–7.

39. Brunelli C, Zecca E, Martini C, Campa T, Fagnoni E, Bagnasco M, et al. Comparison of numerical and verbal rating scales to measure pain exacerbations in patients with chronic cancer pain. Health Qual Life Outcomes. 2010;8(1):42.

40. Williamson A, Hoggart B. Pain: a review of three commonly used pain rating scales. J Clin Nurs. 2005;14(7):798–804.

41. Farrar JT, Young JP, LaMoreaux L, Werth JL, Poole RM. Clinical importance of changes in chronic pain intensity measured on an 11-point numerical pain rating scale. Pain. 2001;94(2):149–158.

42. Pickard AS, Neary MP, Cella D. Estimation of minimally important differences in EQ-5D utility and VAS scores in cancer. Health Qual Life Outcomes. 2007;5(1):70.

43. Pickard AS, De Leon MC, Kohlmann T, Cella D, Rosenbloom S. Psychometric comparison of the standard EQ-5D to a 5 level version in cancer patients. Med Care. 2007;45(3):259–263.

44. Stevens, A, Beurskens, A, Köke, A, Weijden, T. The use of patient-specific measurement instruments in the process of goal-setting: a systematic review of available instruments and their feasibility. Clin Rehabil. 2013;27(11):1005–19.

45. Wester F, Peters V. Kwalitatieve Analyse. Coutinho; 2004. 220 p.

46. Vecht CJ, Hovestadt A, Verbiest HBC, Van Vliet JJ, Van Putten WLJ. Dose-effect relationship of dexamethasone on Karnofsky performance in metastatic brain tumors A randomized study of doses of 4, 8, and 16 mg per day. Neurology. 1994;44(4):675–675.

47. Nederlandse Vereniging voor Anesthesiologie. Wervelkolom gerelateerde pijnklachten van de lage rug. 2011;128.

48. Jensen MP, Turner JA, Romano JM. What is the maximum number of levels needed in pain intensity measurement? Pain. 1994;(58):387–92.

APPENDIX 1 INTERVIEW PROTOCOL

The ambulant status of patients with spinal bone metastasis in the pre- and post- surgery phase; a pilot study. Qualitative research to collect information about the main goals of patients prior to surgery, understand whether patients achieve these goals, gain insight into the type of physical therapy patients receive, in addition to surgery and if preoperative physical therapy training is achievable

Interviewer	Suze Toonders
Requisites	Paper and pen Device for recording Informed consent
Location	Outpatient clinic orthopedics, treatment room
Length	Varies by each interview, estimated at ten minutes

Topics	*Question samples*
Acquaintance	Interviewer introduces herself Objective of the research is explained Sound equipment is introduced
Admission to hospital	- How was your experience in clinical hospitalization? o How many days have you been in hospital? o Did you experience loss of power or condition? ▪ Can you explain this further? ▪ How are you clinically helped to regain your independence? • Physical therapy?
Aftercare	- Which aftercare place you have been gone after discharge? (For example, nursing home, rehabilitation centre, home?) o How was the decision made? - Did you receive physical therapy? o Can you briefly describe what physical therapy implied? o Frequency, duration? - How was aftercare implemented? o Which disciplines? o How would you like to see the implementation of aftercare? These include house treatment, treatment at the outpatient clinic, e-health, etc.
Expectations	- What were your expectations before you went into surgery? o Are these expectations come true? o Would you have a need for preoperative training?
	Patient will be thanking for participating in the study.

APPENDIX 2 PATIENT QUOTES ON THE SEMI-STRUCTURED INTERVIEW

Themes	*Quotes*
Mobility before surgery	"Cannot move leg anymore so test of orthopaedist cannot be accomplished."
	"Walking independently."
	"Not allowed to walk because of paraplegia risk."
	"I really had a lot of pain for ten months.. unbearable ... I was already on a crutch because I just wanted to do things yourself. I wanted to do things on my own in order to preserve my independence, but at one point I was dependent on care. I could no longer use my left leg."
Patients aim after surgery	"Improve condition to enter the radiation as fit as possible."
	"Get better / bit of walking and shop with sister."
	"Independence."
Discharge decision	"I just wanted to go home and they agreed"
	"By the doctors. I also wanted to get home."
	"I myself wanted to go home and the doctors agreed to this."
	"I asked whether it is possible to arrange a small care facility. The decision also went quickly. I had no indication for somewhere to stay here."
Content of physical therapy after discharge	"Mobilization, to walk properly, exercise therapy for muscle strengthening and rules of life perusing together."
	"Exercise therapy for muscle strengthening"
	"Exercise therapy for muscle strengthening, walking and advice regarding transfers"
	"Exercise therapy, the stand out of bed, get up responsibly and how to walk and climb stairs."
Mobility after surgery	"Cannot walking. Short stand and then transfer to the chair. In and out of bed is difficult with help of one person."
	"Short distances unassisted walking greater distances with the walker or wheelchair. Stair climbing cannot. Sitting with a maximum of two hours."
	"I still have a lot of pain in my feet. I can walk alone I have to bite though. I'll save it all but I had really hoped to be more mobile."
Possibility for preoperative training	"Not possible, emergency recording. Operation was within a week."
	"Not possible, emergency recording. Operation was within a week."
	"Not possible due to spinal cord injury risk, surgery was within 2 weeks. It had no meaning for me because I had to be treated as a shelf because they were afraid, I had 90% chance of a spinal cord injury. So I could not move."
	"I have been admitted twice, the second shot was rushed. I would have certainly been open for training prior to the first surgery but do not know whether it had helped because I had such pain in my leg."

Expectations	"Well I did not really have that much expectations because it just went really bad. I could almost nothing. We hoped but it was better than I was, because when I was admitted showed my position in the left leg to be even worse so radiation was not an option anymore." "I expected that I would be more mobile. Expectation that after the operation independently run which would be earlier." "Be more mobile, can move back a little normal. can sit in the scooter to run errands and not just stay in the house." "The aim of the mission was to become independent."