Common format for Evidence Table – Treatment Primary studies

Headings	Description
I Study ID	
1. Reference	First author; Journal name; Publication Date;
II Method	
1. Study design	Specify the type of study: RCT, CCT, case control, case series
2. Source of funding/conflicts of interest	Specify the source of funding: public research funds, government, not governmental organization, healthcare industry or other (give name of organization or corporation) presence of declaration of interest.
3. Setting	Numbers of centers, countries involved, healthcare setting, urban/rural/mixed.
4. Sample size	Give the calculated number in each group and the actual number of patients in each group.
5. Duration of the Study	Duration in months or years.
III Patient characteristics	
1. Eligibility criteria	State the most relevant inclusion and exclusion criteria for population (patients and pathology).
2. Patient characteristics	Specify a priori characteristics (age, tumor, stage).
3. Group comparability	p for group comparability.
IV Intervention(s)	
1. Intervention(s)	Precise details of the interventions for each group (including dose, length, regimen and timing if relevant).
2. Comparator(s)	Placebo, other treatment (including dose, length, regimen and timing if relevant).
V Results primary outcome (GRADE: all outcomes together)	
1. Effect size primary outcome	Summary of the primary outcome in each and between groups: effect size and its precision (p value, CI) Including efficacy: Absolute risk reduction, relative risk (reduction), odds ratios, confidence intervals.
VI Results secondary and all other outcomes	
1. Effect size secondary outcome(s)	Brief description of secondary outcome(s) and p values.
2. Effect size all other outcomes, endpoints	All other outcomes, endpoints, including adverse effects, toxicity, quality of life
VII Critical appraisal of study quality	
1.Level of evidence	Classification of intervention studies.
2. Dropouts	Number of dropouts/withdrawals in each group
3. Results critical appraisal	Summarize internal validity: sample size, randomization and blinding, use of inappropriate statistical analysis, etc

Uitgangsvraag 3

Wat is het effect van verschillende vormen van signaleren van distress/detecteren behoefte zorg op kwaliteit van leven, arts-patiënt communicatie, medische consumptie, ervaren distress en emotionele, psychologische, sociale, psychosociale, praktische, spirituele, levensbeschouwelijke, fysieke problemen, aantal verwijzingen, unmet needs, aangeboden, gewenste en werkelijk gekregen zorg?

Primaire studies: RCT's

Study ID	Method	Patient characteristics	Interventions	Results	Critical appraisal of study quality
Berry 2011 [1]	• Design: RCT • Funding/CoI: public funding; none • Setting: two centres, United States • Sample size: 660 • Duration: April 2005-June 2007; no follow-up (irrelevant for outcomes)	• Eligibility criteria: adult ambulatory patients with any cancer diagnosis, starting a new medical or radiation treatment regimen • *A priori* patient characteristics: intervention vs. control ○ Mean age: 54 vs. 54 years ○ Female: 55% vs. 53% ○ Tumour sites: • Recurrent disease 17 vs. 17% • Lymphoma 16 vs. 14% • Gastrointestinal 12 vs. 12% • Genitourinaria 12 vs. 12% • Leukaemia 4 vs. 17%	ESRA-C + automated summary handed to clinician or attached to file before visit (N=327) vs. ESRA-C without summary(N=333) ESRA-C :patient-reported cancer symptoms and quality-of-life issues were automatically displayed on a graphical summary and provided to the clinical team before an on-treatment visit. Each symptom or quality of life issue reported at or above a predetermined threshold was flagged by color and height of a bar graph. In the control group, no summary was provided. No recommendations were offered to address any reported symptoms or quality of life issues	Distress: Not reported on Quality of life: Not reported on Unmet needs: Not reported on Communication: Were self-reported symptoms or quality of life issues discussed during clinical visit yes/no: The likelihood of symptoms or quality of life issues being discussed differed by randomized group and depended on whether symptoms or quality of life issues were first reported as problematic (p=0.032). The odds ratio effect estimate for no problematic issues or symptoms was 1.007 (95%CI: 0.885 to 1.131). The odds ratio effect estimate for problematic issues or symptoms was 1.287 (95%CI: 1.047 to 1.583) Medical treatment during follow-up: Not reported on Referrals: Not reported on Proposed/wished/received care: Not reported on	Level of evidence: high risk of bias; B (EBRO) • Non-blinded study; unclear whether outcome assessors were blinded • 105 patients that entered the study were not randomized (originally 765 patients entered the study). These patients withdrew from the study voluntarily (n=15) or involuntarily (death: n=30) or were lost to follow-up (n=60) before randomisation • 38 vs. 32 patients were not analysed as they refused to be recorded, or the recording was incomplete or there were technical problems with the recording

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Braeken 2013 [2, 3]	• Design: cluster RCT • Funding/CoI: public funding; no CoI to report • Setting: single centre, the Netherlands • Sample size: N=14 radiotherapist, 568 patients • Duration: Apr 2008-Oct 2010; questionnaires at 3 and 12 months of follow-up	• Eligibility criteria: patients receiving radiotherapy at a radiation oncology department, with a cancer diagnosis of the lung, prostate, bladder, rectum, breast, cervix, skin, endometrial or Non-Hodgkin lymphoma; age over 18 years; no metastases. Exclusion: palliative treatment; had ≤10 fractions of radiotherapy; were unable to read and speak Dutch; or were unable to complete the questionnaires • *A priori* patient characteristics: intervention vs. control ○ Mean age: 62 vs. 62 years ○ Female: 68% vs. 53% (p<0.01) ○ Tumour sites differed significantly with more prostate/bladder and lung cancer in the control group, and more breast and rectum cancer in the experimental group	SIPP (N=268) vs. Treatment as usual (N=300) SIPP: ´The seven radiotherapists in the experimental group received a training in using and interpreting the SIPP. Patients received the SIPP twice: just before the first consultation with the radiotherapist and before the consultation at the end of the RT. On both occasions, the radiotherapists checked the scores to obtain an overview of psychosocial problems and the patient's needs and/or preference for psychosocial care. A manual was prepared with suitable cut-off scores of the SIPP. Potential referral for psychosocial support was based on the scores of the SIPP in combination with the judgement of the radiotherapists concerning the patient's needs and/or preferences for psychosocial care´	<u>Distress (GHQ-12, HADS), mean (SD)</u>: ´ No significant intervention effects were observed for patients' extent of psychological distress and the proportion of patients with distress, both on the short and long terms.´ Distress 3 months: 2.74 (3.26) vs. 2.85 (3.38) (p=0.19) 38.4% vs. 39.0% (p=0.36) had moderate-high extent distress (score ≥3) 12 months: 1.96 (3.14) vs. 2.14 (3.22) (p=0.12) 24.3% vs. 24.7% (p=0.39) had moderate-high extent distress (score ≥3) Anxiety 3 months: 4.66 (3.68) vs. 4.86 (3.81) (p=0.44) 21.3% vs. 21.3% (p=0.15) had moderate-high extent anxiety (score ≥8) 12 months: 4.57 (3.90) vs. 4.98 (4.24) (p=0.33) 15.7% vs. 20.3% (p=0.50) had moderate-high extent anxiety (score ≥8) Depression 3 months: 3.69 (4.11) vs. 3.72 (3.76) (p=0.25) 6.3% vs. 7.7% (p=0.11) had moderate-high extent depression (score ≥8) 12 months: 3.45 (3.78) vs. 3.70 (4.08) (p=0.49) 17.2% vs. 15.3% (p=0.49) had moderate-high extent depression (score ≥8) <u>Quality of life (EORTC-QoLQ)</u>: ´ No significant intervention effects were observed on HRQoL on the short and long terms. Although, the control group patients reported better role functioning on the short term compared with patients in the experimental group (p=0.04)´ 5 functional subscales, 3 symptom subscales and and 6 single symptoms reported on + global health status <u>Unmet needs</u>: Not reported on	Level of evidence: high risk of bias; B (EBRO) • High risk of bias because personnel was not blinded, and because of selective reporting (see below) • Randomisation at the level of 14 radiotherapists • 49.4% of eligible patients refused to participate in the study • Not described what the ´suitable cut-off´ for the SIPP was • Contamination possible as small number of radiotherapists working in one centre are involved, though ´Radiotherapists of the experimental condition are asked not to discuss this study with their colleagues of the control condition.´ • Patient satisfaction with communication was a primary outcome but not reported on (selective reporting)

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			Care as usual: ´No guidelines for routinely screening of psychosocial problems in patients existed. However, as part of standard care, radiotherapists may refer control patients to psychosocial caregivers (social workers) at BVI. The latter occurs according to the radiotherapist's personal judgment concerning the presence or absence of psychosocial problems in patients.´	Communication: Not reported on Medical treatment during follow-up: Not reported on Referrals: Not reported on Proposed/wished/received care: Not reported on	
Carlson 2010 [4, 5]	• Design: RCT • Funding/CoI: public funding; no CoI to report • Setting: single centre, Canada • Sample size: N=1134 • Duration: May 2006-Oct 2007; 3 months follow-up	• Eligibility criteria: new (newly diagnosed, or new to a particular oncologist or the specific clinic) patients with breast and lung cancer, attending outpatients clinics • *A priori* patient characteristics: intervention vs. control ○ Mean age 64 vs. 62 vs. 63 years ○ 26% vs. 26% vs. 29% male ○ 48% lung cancer; 52% breast cancer ○ 87% vs. 85% vs. 89% had not had any interventions at the time of randomisation	Minimal screening: the distress thermometer + usual care. No feedback was given to the patient or placed in their medical record (N=365) vs. Full screening: distress thermometer, problem checklist, Psychological Screen for Cancer part C measuring anxiety and depression, a personalized report summarizing concerns and the report on the medical file (N=391) vs. Triage: full screening	Distress and other problems at 3 months: Over distress thermometer cut off of ≥4: 48.7% vs. 46.0% vs. 36.0% (p<0.01) ○ Lung cancer: 51.3% vs. 50.9% vs. 30.7% (p<0.001) ○ Breast cancer: 46.8% vs. 43.2% vs. 40.6% PSSCAN Anxiety mean (SD): 7.69 (3.60) vs. 7.49 (3.30) vs. 7.61 (3.58) PSSCAN depression mean (SD): 7.76 (3.21) vs. 7.74 (2.83) vs. 7.73 (3.06) Pain thermometer (reported for lung cancer patients only): Pain in lung cancer patients: 49.6% vs. 40.7% vs. 32.1% (significant difference between triage and minimal screening, p=0.005) Clinically elevated pain in lung cancer patients: 33.3% vs. not reported vs. 21.9% (p=0.04) No significant differences were found between the groups on mean pain scores (2.61 vs. 2.11 vs. 1.82, p = 0.142) Fatigue thermometer (reported for lung cancer	Level of evidence: high risk of bias; B (EBRO) • Non-blinded personnel, incomplete data (high loss to FU at 3 months FU only) and selective reporting (the secondary analysis was reported for lung cancer patients only) • 75.5% of patients were retained in follow-up • A score of ≥4 on the distress thermometer was taken as cut-off • There was an extensive triage algorithm in place for referral to coping class/psychological resources/resource class/social worker/pain clinic/fatigue clinic/fatigue nurse/nutrition class/nutritionist for the triage group

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			plus optional personalized phone triage with referral to resources (N= 378) by a member of the screening for distress team Across conditions all patients were provided with an educational information package including program descriptions and self-referral information to the Department of Psychosocial Resources and cancer center programs. All patients were able to self-refer to services	patients only): Fatigue in lung cancer patients: no significant differences were found between the groups on mean fatigue scores (3.74 vs. 3.32 vs. 3.86, p=0.43) (other data not reported) Canadian Problem checklist (reported for lung cancer patients only): Mean total physical problems: 1.61 vs. 1.53 vs. 1.24, p = 0.29 Mean total psychosocial problems: 1.03 vs. 0.82 vs. 0.85, p=0.19 Mean total practical problems: 0.47 vs. 0.45 vs. 0.46, p=0.23 Problems with coping: 23.9% vs. 26.9% vs. 12.9%, p = 0.017 Problems with family conflict: fewer triage patients reported problems with family conflict compared with the minimal screening group p=0.05) and fewer full screening patients reported problems with family conflict compared with the minimal screening group (p=0.015). Breathlessness: fewer patients in the full screening group reported breathlessness than the minimal screening group (p=0.03). There was a trend for fewer triage patients to report problems with breathlessness than the minimal screening group (p=0.06) (actual data not reported) <u>Quality of life</u>: Not reported <u>Unmet needs</u>: Not reported <u>Communication</u>: Not reported <u>Medical treatment during follow-up</u>: Not reported <u>Referrals</u>: Self-referral: 10.4% vs. 14.3% vs. not reported Self-referral or referred up to 3 month follow-up:	• 46.3% of patients in the triage group requested to speak to staff in a phone triage; 38.6% were successfully contacted and 22.8% received referral before follow-up and 6.9% after follow-up • 3 months follow-up only

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				16.2% vs. 23.8% vs. 22.8% Self-referral or referred including after follow-up: 20.8% vs. 28.6% vs. 29.6% Proposed/wished/received care: Not reported	
Detmar 2002 [6]	• Design: randomised cross-over trial • Funding/CoI: public funding; not reported on • Setting: single centre, the Netherlands • Sample size: 10 physicians, 273 patients • Duration: June 1996-June 1998; follow-up up to 4th visit	• Eligibility criteria: physicians: oncologists working in the oncology department. Patients: consecutive outpatients receiving palliative chemotherapy • *A priori* patient characteristics: intervention vs. control ○ Mean age: 58 vs. 55 years ○ Female:73% vs. 81% ○ Tumour sites: 41% vs. 62% breast cancer (p=0.03); 18% vs. 16% colorectal; 18% vs. 10% other	EORTC-QLQ-C30 (N=145) vs. Unspecified, presumably TAU (N=128) Patients in the intervention group were screened at 3 consecutive outpatient visits; responses were computer scored and transformed into a graphic summary, of which physicians and patients received a copy before the consultation. Each physician had received a single half hour session on how to interpret QLQ-C30 summary scores, and patients received a similar explanation in a pamphlet mailed to their home	Distress: Not reported on Quality of life (SF-36): No statistical significant between-group differences for any scale at 4th visit Improvement over time (0.5 SD-unit or greater change): Mental health: 43 vs. 30% (p=0.04) Role functioning: 22 vs. 11% (p=0.05) Other subscales not reported on Unmet needs: Not reported on Communication: Composite communication score at 4th visit: (score summing all health related quality of life issues that were discussed, range 0-12): 4.5 (SD: 2.3) vs. 3.7 (SD: 1.9) (p=0.01) Social functioning (p=0.05), fatigue (p=0.02), dyspnea (p=0.02) were discussed more frequently in the intervention group Medical treatment during follow-up: No statistical differences in the prescription of medication or the ordering of tests from visit 1-4 (actual data not reported) Referrals: No statistical difference between groups from visit 1-4 (actual data not reported) Proposed/wished/received care: Not reported on	Level of evidence: high risk of bias; B (EBRO) • Cross-over design with evidence of a carryover effect; sequence generation and allocation concealment unclear; blinded outcome assessment of composite communication score • Physicians were assigned at random to initially either the intervention or control group and switched after a wash-out period of 2 months • For each physician at least ten consecutive patients were invited to participate • Loss to follow-up of around 30% in each patient group for similar reasons
Girgis 2009 [7]	• Design: RCT • Funding/CoI: public funding; no CoI to report	• Eligibility criteria: non-localized breast or colorectal cancer, notification within 6 months of	Telephone caseworker (TCW) model (N=120)	Distress: HADS anxiety elevated scores at 6 months: 13.0% vs. 17.1% vs. 16.8% (p=0.64)	Level of evidence: high risk of bias; B (EBRO)

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	• Setting: single centre, Australia • Sample size: N=356 • Duration: Sept 2003-Jan 2006; follow-up 6 months	diagnosis • *A priori* patient characteristics: intervention vs. control ○ Mean age: 58 vs. 58 vs. 57 years ○ 28% males in each group ○ 49% breast cancer in all groups ○ Mean time since diagnosis 6 months in all groups	vs. Oncologist/general practitioner (O/GP) model (N=119) vs. TAU (N=117) Data collected from participants in the supportive care models were used to generate feedback to either each participant's designated TCW, or their nominated O/GPs. Data were summarized with issues of concern and suggested management strategies. TCWs were nurses with telephone counseling training who received 1 day of training in study methodology. TCWs telephoned participants to discuss reported issues of concern and used a modified version of the cancer helpline database to refer participants to appropriate resources/services consistent with recommended	HADS depression elevated scores at 6 months: 3.5% vs. 4.8% vs. 5.3% (p=0.80) <u>Quality of life</u>: Mean EORTC-QoLQ at 6 months (SD): Role functioning 88.7 (22.8) vs. 86.0 (21.9) vs. 86.6 (22.7) (p=0.65) Emotional functioning 86.7 (18.7) vs. 88.7 (17.3) vs. 84.4 (18.9) (p=0.23) Cognitive functioning 85.4 (21.6) vs. 86.2 (20.7) vs. 84.8 (21.8) (p=0.89) Social functioning 91.9 (17.6) vs. 92.2 (15.0) vs. 91.9 (17.4) (p=0.99) Physical functioning 93.1 (9.95) vs. 88.4 (14.4) vs. 88.8 (13.3) (p=0.01) QoL 79.9 (17.4) vs. 79.2 (19.2) vs. 78.6 (16.7) (p=0.85) <u>Unmet needs</u>: One or more unmet supportive care needs at 6 months: 49.6% vs. 61.0% vs. 63.7% (p=0.07) <u>Communication</u>: TCW group participants were more likely to strongly agree that study participation had made discussions with their health care practitioners easier (p=0.0005) <u>Medical treatment during follow-up</u>: Not reported <u>Referrals</u>: TCW participants were more likely to have referrals recommended (p=0.0001), in particular for unmet psychological (p=0.01), daily living (p=0.01), health service/information (p=0.01), and physical (p=0.01) needs <u>Proposed/wished/received care</u>: Not reported	• Non-blinded study • Low loss to follow-up (<10%), similar across groups with reasons given • Unclear which HADS scores were deemed elevated. It was stated that: ´[…] classifies anxiety and depression levels separately as low/normal (0 to 7), borderline/ subclinical (8 to 10), or clinically significant (11 to 21) • Screening took place with the HADS, EORTC-QoL, Supportive Needs Survey-Short Form, and a single question on communication with health care professionals

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			feedback sheet strategies. If no issues of concern were identified, TCWs contacted participants to confirm they had no immediate concerns. TCWs also followed up participants at 6-week intervals to assess coping. For O/GP group participants, two hard copies of feedback sheets were mailed to both the participants' nominated oncologists and GPs for discussion at their next appointments		
Hollingworth 2013 [8]	• Design: RCT + cost-effectiveness analysis • Funding/CoI: public funding; no CoI to report • Setting: two centres, United Kingdom • Sample size: N=220 • Duration: Oct 2009-Feb 2011; 12 months follow-up	• Eligibility criteria: primary solid tumor diagnosis within previous 12 months; outpatient external radiotherapy over a period of ≥ 2 weeks or outpatient chemotherapy of ≥ 2 cycles; not receiving neoadjuvant chemotherapy; not diagnosed with ductal carcinoma in situ or skin carcinoma • *A priori* patient characteristics: intervention vs. control ○ Mean age 61 vs. 62 years ○ Female 68% vs. 60% ○ Breast cancer 54% vs. 45% ○ Urological cancer 24% vs. 31% ○ 37% of patients in the intervention group had a distress thermometer score ≥4; 84% reported any physical problem; 56%	Distress thermometer and problem list + TAU (N=112) vs. TAU (N=108) All staff attended a training session including an audiovisual example of distress thermometer and problem list administration, role playing, and advice on dealing with strong emotions. The instruments were filled in and discussed with a radiographer/nurse and formed the basis	<u>Distress(mean POMS score (SD))</u>: ○ 6 months: 34.46 (20.87) vs. 34.87 (22.00) ○ 12 months: 34.46 (20.87) vs. 34.87 (22.00) ○ Overall adjusted difference in means over 12 months: -1.84 (95%CI: -5.69 to 2.01, p=0.35) <u>Quality of life (mean EORTC QoLC30 (SD))</u>: Global: ○ 6 months: 68.6 (17.7) vs. 68.3 (18.2) ○ 12 months: 68.5 (20.2) vs. 69.6 (20.4) ○ Overall adjusted difference in means over 12 months: 1.54 (95%CI: -1.83 to 4.91, p=0.37) Physical: ○ 6 months: 84.2 (19.0) vs. 83.8 (18.6) ○ 12 months: 83.8 (19.3) vs. 85.5 (17.8) ○ Overall adjusted difference in means over 12 months: 3.14 (95%CI: 0.29 to 6.00, p=0.031) Role: ○ 6 months: 79.2 (24.9) vs. 79.7 (27.6) ○ 12 months: 80.5 (26.4) vs. 84.1 (21.9) ○ Overall adjusted difference in means over 12	Level of evidence: high risk of bias; B (EBRO) • Non-blinded study • Low loss to follow-up of around 5% in both groups with similar reasons • Screening with distress thermometer was done in the second week of radiotherapy/second cycle of chemotherapy approximately. At the discretion of the patient, a second DT&PL meeting could be arranged toward the end of therapy (5% of patients did so)

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		reported any emotional problem; 39% reported any other problem (most frequently questions about illness/treatment 12%)	of a therapeutic conversation where concerns were identified and potential solutions are discussed including immediate staff actions (e.g. providing information), patient actions (e.g. using a self-help resource), and referral (e.g. psychological counseling). A resource directory was developed providing information on self management techniques, information sources, and support groups and guidance for staff on when to refer patients. Referrals were at the discretion of the clinician. No formal triage criteria were implemented as the instruments were predominantly used as a needs assessment tool, enabling patients to discuss concerns that might be addressed through immediate staff and patient actions TAU: if patients expressed concerns about physical or psychosocial issues, then staff discussed these issues as	months: 0.67 (95%CI: -4.11 to 5.46, p=0.78) Emotional: ○ 6 months: 81.2 (18.0) vs. 80.3 (20.7) ○ 12 months: 78.7 (21.6) vs. 80.3 (21.4) ○ Overall adjusted difference in means over 12 months: -0.50 (95%CI: -3.95 to 2.94, p=0.77) Cognitive: ○ 6 months: 81.0 (20.3) vs. 80.7 (19.7) ○ 12 months: 82.9 (18.6) vs. 79.8 (22.5) ○ Overall adjusted difference in means over 12 months: -1.93 (95%CI: -5.76 to 1.89, p=0.32) Social: ○ 6 months: 78.3 (26.8) vs. 78.2 (28.2) ○ 12 months: 81.3 (27.5) vs. 84.0 (23.4) ○ Overall adjusted difference in means over 12 months: 3.51 (95%CI: -1.36 to 8.39, p=0.16) <u>Unmet needs</u>: Not reported <u>Communication</u>: Not reported <u>Medical treatment during follow-up (mean per patient)</u>: Inpatient care: 2.0 vs. 1.4 days Outpatient hospital visits: 4.7 vs. 4.1 Emergency department visits: 0.1 vs. 0.1 Medication types: 13.0 vs. 10.7 GP visits: 5.2 vs. 4.7 Nurse visits: 3.6 vs. 2.4 Psychologist visits: 0.2 vs. 0.6 Other community care visits: 4.2 vs.3.9 <u>Referrals</u>: 2/112 (1.8%) vs. 3/108 (2.8%) patients consulted a clinical psychologist (referrals were discussed more extensively, but this is only described for the thermometer group, e.g. clinical psychology contact discussed 7%, counselling discussed 6%, support group discussed 6% etc.)	

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			normal, offering advice or making a referral. No formal time was set aside to monitor patient distress using the DT, elicit problems using the PL, or develop a plan of action	Proposed/wished/received care: Not reported	
Klinkhammer-Schalke 2012 [9]	• Design: RCT • Funding/CoI: public funding; CoI not reported on • Setting: multicenter, Germany • Sample size: N=200 • Duration: Sep 2004-Oct 2007; follow-up 12 months after surgery	• Eligibility criteria: primary breast cancer operated on, before hospital discharge • *A priori* patient characteristics: intervention vs. control ○ Median age 58 vs. 57 years	Quality of life pathway (N=100) vs. TAU (N=100) Quality of life pathway: screening with EORTC QLQ-C30, plus breast cancer module QLQ-BR23. Each patient's QoL response was transformed into a profile which was handed out to five experts in the QoL unit who independently formulated their QoL diagnosis and treatment recommendations. The QoL profile, health status form and individual expert decisions were discussed weekly at consensus meetings of the five experts, resulting in an expert consensus report. This was sent immediately to the coordinating practitioners of	Distress: Not reported Quality of life: Diseased QoL in at least one dimension at 6 months: 56% vs. 71% (p=0.048) 21% relative risk reduction (95%CI: 0-37%) 15% absolute risk reduction (95%CI: 0.3-29%) NNT: 7 (95%CI: 3-37) At 9 and 12 months there were also more healed patients in the QoL pathway group, though the difference was no-significant (actual data reported in graph only) The difference was only significantly better in the emotional subscale at six months Unmet needs: Not reported Communication: Not reported Medical treatment during follow-up: Not reported Referrals: At 3 months: 21/92 (23%) vs. 12/99 (12%) patients received coping strategies and counselling (p<0.55) 10 (11%) vs. 1 (1%)patients received psychotherapy (p<0.05) 18 (20%) vs. 25 (25%) patients received physiotherapy (ns)	Level of evidence: low risk of bias; A2 (EBRO) • Only a high risk of bias for the outcome referrals, as professionals were non-blinded • 15% loss to FU in both groups with stated and similar reasons • Diseased QoL was defined as a drop below 50 points in any of the 10 major QoL dimensions on a scale from 100 to 0 points (worst QoL). Healed QoL was a shift to 50 points or more one any scale • QoL was measured before discharge and at 3, 6, 9 and 12 months FU • Coordinating practitioners were trained in the quality of life pathway method, in both treatment groups • Treatment was stopped if QoL was healed

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			intervention patients. Therapeutic options could be: physiotherapy, psychotherapy, social support, pain therapy, nutrition and/or fitness. The coordinating practitioners received a follow-up call from the quality of life team to inquire what actions had been taken re the consensus report TAU: similar screening, however, neither QoL profile nor expert report were transmitted to coordinating practitioners	At 6 months: 19 (21%) vs. 10 (10%) patients received coping strategies and counselling (ns) 3 (3%) vs. 3 (%) patients received psychotherapy (ns) 16(17%) vs. 30 (30%) patients received physiotherapy (p<0.02) <u>Proposed/wished/received care</u>: Not reported	
Kornblith 2006 [10]	• Design: RCT • Funding/CoI: public funding; not reported on • Setting: multicenter study, United States • Sample size: 192 • Duration: Sept 1998-Jan 2003; follow-up: 9 months	• Eligibility criteria: patients aged 65 years and older with breast, prostate, and colorectal cancers who had advanced disease and currently were receiving treatment initiated ≤2 months prior • *A priori* patient characteristics: intervention vs. control ○ Age: 38 vs. 35% aged 70-79 years ○ Female: 33 vs. 29% ○ Tumour sites: 25 vs. 22% breast cancer; 20 vs. 20% colorectal cancer; 24 vs. 20% colorectal cancer	Monthly telephone monitoring for six months with the HADS and EORTC physical symptom items and the MOS Social Support Survey items + educational materials (N=69 analysed) vs. Educational materials (N=66 analysed) Cutoff levels were established to indicate which patients were in greater distress. Those patients who scored above the	<u>Distress at 6 months (HADS):</u> Overall distress: 6.01 (4.95) vs. 8.20 (5.59), p<0.0001 Anxiety: 2.81 (2.65) vs. 3.25 (3.39), p<0.0001 Depression: 3.20 (2.92) vs. 4.08 (2.85), p=0.0004 <u>Quality of life (EORTC at 6 months):</u> Total: 64.79 (20.71) vs. 65.55 (20.40), p=0.24 Emotional functioning: 84.44 (15.30) vs. 82.91 (16.18), p=0.15 Physical symptoms: 19.46 (12.53) vs. 19.58 (12.29), p=0.25 Physical functioning: 65.15 (22.09) vs. 69.67 (23.50), p=0.28 <u>Unmet needs</u>: Not reported on <u>Communication</u>: Not reported on <u>Medical treatment during follow-up</u>:	Level of evidence: high risk of bias; B (EBRO) • Unclear risk of selection bias; non-blinded study; high attrition; high risk of attrition bias • 131 (69 vs. 66) patients completed both the base-line and 6 months follow-up assessment and were analysed; 39 patients were not randomised • Patients who were evaluated both at study entry and at 6 months had significantly lower HADS Depression subscale scores (p=0.03), higher EORTC Emotional Functioning subscale scores (p=0.01), and higher EORTC Role

<table>
<tr><th>Study ID</th><th>Method</th><th>Patient characteristics</th><th>Interventions</th><th>Results</th><th>Critical appraisal of study quality</th></tr>
<tr><td></td><td></td><td></td><td>cutoff levels were referred to their oncology nurse for referral to the appropriate professional. Patients in the control group received written materials regarding cancer-related psychosocial issues and available resources</td><td>Not reported on

<u>Referrals</u>:
27 vs. 2 patients were referred by the oncology nurse to either a psychiatrist/psychologist, social worker/social services, oncologist, or oncology nurse: unclear how to interpret these findings, what is a referral by an oncology nurse to an oncology nurse?

<u>Proposed/wished/received care</u>:
Not reported on</td><td>Functioning subscale scores (p=0.02) at baseline compared with the patients who were not assessed at both time points
• Patients in the control group were also referred to the oncology nurse when they were evaluated at study entry, at 6 months, and at 9 months if they were distressed significantly and scored above the same cutoff levels as patients in the intervention group. These referrals were lower, e.g. 45 vs. 5 for physical problems, 29 vs. 15 for psychological problems, and 4 vs. 3 for social problems</td></tr>
<tr><td>McLachlan 2001 [11]</td><td>• Design: RCT
• Funding/CoI: public funding; CoI not reported on
• Setting: single centre, Australia
• Sample size: N=450
• Duration: March 1999-; follow-up 6 months</td><td>• Eligibility criteria: diagnosis of lung, head and neck, genitourinary, skin, or other cancers managed in the medical oncology clinic, of any clinical stage, not attending for the very first consultation, adequate proficiency in English language, Eastern Cooperative Oncology Group performance status _≤2, age ≥18 years, adequate follow-up scheduled at the institute, written informed consent, and completion of ≥90% of questionnaire items on prestudy assessment. Patients receiving treatment for a major psychiatric or cognitive disorder were excluded, as were patients with breast cancer, because there were competing quality of life studies for these patients
• A priori patient characteristics:</td><td>Questionnaires (CNQ-SF + EORTC QLQ-C30 + BDI-SF) + individualized management plan (N=296)

vs.

Same questionnaires + TAU (N=154)

Questionnaires + management plan: a computer-generated one-page summary of the questionnaire results was made available immediately for consideration during the consultation with the doctor. The coordination nurse was also present</td><td><u>Distress</u>:
Not reported on

<u>Anxiety</u>:
Not reported on

<u>Depression (BDI-SF)</u>:
Difference between the mean changes from baseline scores for the two arms, expressed so that a positive difference indicates a benefit for the intervention arm relative to the control arm: 0.6 (95%CI: -0.1 to 0.3, p=0.07)

<u>Quality of life(EORTC QLQ-C30</u>:<table><tr><th></th><th>*</th><th>95%CI</th><th>p</th></tr><tr><td>Cognitive functioning</td><td>1.4</td><td>-2.6-5.5</td><td>0.48</td></tr><tr><td>Emotional functioning</td><td>1.4</td><td>-2.9-5.7</td><td>0.52</td></tr><tr><td>Global health status/QOL</td><td>2.5</td><td>-2.2-7.1</td><td>0.29</td></tr><tr><td>Physical functioning</td><td>4.6</td><td>-0.1-9.4</td><td>0.06</td></tr><tr><td>Role functioning</td><td>2.0</td><td>-5.6-9.5</td><td>0.61</td></tr><tr><td>Social functioning</td><td>0.9</td><td>-4.2-5.9</td><td>0.73</td></tr></table>*Difference between the mean changes from baseline scores for the two arms, expressed so that a positive difference indicates a benefit for</td><td>Level of evidence: high risk of bias; B (EBRO)

• Unclear risk of selection bias (sequence generation and allocation concealment not described), professionals non-blinded
• Similar drop-out rate of around 15%, for similar reasons
• 74% of patients in the intervention arm were offered on average 2 services; 37% of offered services were accepted; the most frequent reasons for refusal were related to timing and priorities, a preference for other forms of support or self-management, and a belief that the services offered were unnecessary or would</td></tr>
</table>

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<tr>
<td></td>
<td></td>
<td>intervention vs. control
○ Median age: 61 years
○ Female: not reported
○ Tumour sites: 29% vs. 29% lung cancer ; 20% vs. 22% head and neck cancer; 18% vs. 17% gynaecological cancer
○ Current treatment: 38% vs. 37% none; 25% vs. 26% supportive care only; 32% vs. 33% radiotherapy and/or chemotherapy</td>
<td>during this consultation. After discussion with the patient and doctor, the coordination nurse formulated an individualized management plan based on the issues raised in the summary report and prespecified psychosocial guidelines. Prespecified psychosocial guidelines were formulated by a group of multidisciplinary experts. They were developed to be linear single pathways broadening to multiple options. It was the responsibility of the nurse to implement the plan and involve other members of the health care team, as appropriate. No instructions were specifically given to clinicians regarding use of the patient-reported information

Questionnaires + TAU: conventional clinical encounter, and the self-reported information was not made available to the health care professionals at any</td>
<td>the intervention arm relative to the control arm

Unmet needs (CNQ):
<table>
<tr><th>*</th><th>Mean</th><th>95%CI</th><th>p</th></tr>
<tr><td>Psychologic</td><td>-0.004</td><td>-4.6-4.6</td><td>1.00</td></tr>
<tr><td>Health information</td><td>-0.6</td><td>-8.9-7.7</td><td>0.89</td></tr>
<tr><td>Physical and daily living</td><td>0.01</td><td>-4.9-5.0</td><td>1.00</td></tr>
<tr><td>Patient care and support</td><td>2.7</td><td>-3.3-8.7</td><td>0.38</td></tr>
<tr><td>Interpersonal communication</td><td>-0.4</td><td>-4.6-3.9</td><td>0.87</td></tr>
<tr><td>Additional Items</td><td></td><td></td><td></td></tr>
<tr><td>Sex/intimacy</td><td>0.9</td><td>-5.5-7.3</td><td>0.78</td></tr>
<tr><td>Spirituality/religious</td><td>-6.6</td><td>-12.0--1.3</td><td>0.02</td></tr>
</table>
*Difference between the mean changes from baseline scores for the two arms, expressed so that a positive difference indicates a benefit for the intervention arm relative to the control arm

Communication:
Not reported on

Medical treatment during follow-up:
Not reported on

Referrals:
Not reported on

Proposed/wished/received care:
Not reported on</td>
<td>not help. The most frequently offered services were counselling (30% of services offered) and physical symptom management (20%). Significantly more patients accepted referrals for physical symptom management than for counselling (57% v 28%, respectively; p=0.0003</td>
</tr>
</table>

Study ID	Method	Patient characteristics	Interventions	Results	Critical appraisal of study quality
			time. For ethical reasons, however, if a control group patient reported a serious concern (eg, suicidal ideation), then the care coordination nurse was permitted to inform the appropriate health professionals		
Maunsell 1996 [12]	• Design: RCT • Funding/CoI: public funding; not reported on • Setting: single centre, Canada • Sample size: N=261 • Duration: 1990-1992; follow-up: 12 months	• Eligibility criteria: newly diagnosed breast cancer patients with localized or regional stage disease first treated at the centre • A priori patient characteristics: intervention vs. control ○ Mean age: 55 vs. 56 years ○ Female: all ○ Tumour sites: breast only	GHQ telephone screening every 28 days (N=123) + telephone contact by social worker for high scoring patients vs. Treatment as usual (N=127) Intervention: telephone contact by social workers was used to elicit whether patients wanted additional social worker contact. No formal triage	Distress (PSI mean score): 13.5 (SD: 12.1) vs. 14.6 (SD: 12.3) (p not reported) Anxiety: Not reported on Depression: Not reported on Quality of life: Health felt to be good or excellent: 79.7% vs. 79.5% Worry about health moderately or a lot: 29.3% vs. 33.1% Unmet needs: Not reported on Communication: Not reported on Medical treatment during follow-up: Family physician consult: 77.2% vs. 77.2% Other physician: 43.2% vs. 38.6% Alternative medicine: 19.5% vs. 15.0% Psychiatrist/psychologist: 12.2% vs. 11.8% (all non-significant, p-values not reported) Referrals: Not reported on Proposed/wished/received care: Not reported on	Level of evidence: high risk of bias; B (EBRO) • low risk of selection bias, high risk of detection and attrition bias • In this clinic, a universal but minimal psychosocial follow-up care program was already in place for newly diagnosed patients. Controls had access to these services. Basic psychosocial follow-up care provided by the social worker was based on a brief crisis intervention model. Specifically, this care included a contact with each patient during initial hospitalization to assess patients' immediate reaction to surgery, to identify those experiencing difficulties associated with diagnosis and treatment, and to let patients know that individual help was available from the social worker if needed. Volunteers who were recovered breast cancer patients were also available for individual meetings with new patients

Study ID	Method	Patient characteristics	Interventions	Results	Critical appraisal of study quality
					• GHQ scores ≥ 5 were considered high scores • No ITT analysis, analysis based on 250 women. 8 vs. 3 women excluded from analysis
Rosenbloom 2007 [13]	• Design: RCT • Funding/CoI: public funding; not reported on • Setting: single centre, United States • Sample size: N=213 • Duration: 1990-1992; follow-up: 6 months	• Eligibility criteria: metastatic breast, lung or colorectal cancer, receiving chemotherapy, life expectancy of at last 6 months • A priori patient characteristics: intervention vs. control ○ Mean age: 57 vs. 60 vs. 61 years ○ Female: 67% vs. 70% vs. 67% ○ Tumour sites: mixed	FLIC + relevant subscales + structured interview and discussion + TAU at 1, 2, 3, and 6 months (N=69) vs. FLIC + relevant subscales at 1, 2, 3 and 6 months + TAU (N=73) vs. Treatment as usual (N=71) Structured interview: patients were interviewed by the research nurse after questionnaire completion for more detailed HRQL feedback, which was then relayed to the treating nurse, no formal triage FLIC group without structured interview: HRQL results were presented to the treating nurse after the questionnaires were completed, no formal	Distress (POMS-17 NEG (SD)): 8.1 (8.5) vs. 8.1 (9.5) vs. 8.3 (8.2) Anxiety: Not reported on Depression: Not reported on Quality of life (mean FLIC total (SD)): 115.8 (22.9) vs. 113.3 (24.5) vs. 112.2 (21.4) Unmet needs: Not reported on Communication (Communication Satisfaction Subscale from PSQ-III (SD)): 21.2 (2.8) vs. 21.2 (3.0) vs. 20.8 (3.2) Medical treatment during follow-up: Not reported on Referrals: Not reported on Proposed/wished/received care: Not reported on	Level of evidence: high risk of bias; B (EBRO) • Unclear risk of selection bias, personnel non-blinded, unclear for patients • Non-differential loss-to follow-up, for similar reasons • 15 years between recruitment and publication • FACT-G was assessed around every month

Study ID	Method	Patient characteristics	Interventions	Results	Critical appraisal of study quality
			triage		
Ruland 2010 [14]	• Design: RCT • Funding/CoI: • Setting: single centre, Norway • Sample size: 145 • Duration: not reported; follow-up: median follow-up not reported	• Eligibility criteria: patients starting treatment for leukemia or lymphoma • *A priori* patient characteristics: intervention vs. control ○ Mean age: 50 vs. 49 years ○ Female: 40 vs. 36% ○ Tumour sites: lymphoma 77 vs. 76%; leukemia: 21 vs. 17%	Computer assisted, interactive tailored patient assessment tool with symptom assessments prior to inpatient and outpatient visits (N=75) vs. Placebo assessment (N=70) The automated assessment summary, which displayed patients' self-reported symptoms, problems, and distress in rank-order of the patient's need for support, was provided to physicians and nurses in the intervention group only but not in the control group. No formal triage or referral algorithm in place	<u>Distress (Choice instrument)):</u> Group differences were statistically significant in favor of the intervention group for four out of the 19 categories: discomfort, eating/drinking, sleep/rest, and sexuality (data reported graphically) <u>Quality of life:</u> Not reported on <u>Unmet needs</u>: Need for symptom management support (Choice instrument): group differences were statistically significant in favor of the intervention group in 13 of 19 (68%) categories (data reported graphically) <u>Communication</u>: Not reported on <u>Medical treatment during follow-up</u>: Not reported on <u>Referrals</u>: Not reported on <u>Proposed/wished/received care</u>: Not reported on	Level of evidence: high risk of bias; B (EBRO) • Low risk of selection bias; high risk of performance and outcome assessment bias due to unblinded nature • 30% attrition over unreported median follow-up • Patients in this study first selected from among 19 problem categories any that applied to them, for example 'eating and drinking problems'. This triggered a subset of more specific symptom descriptions in lay terms from which patients again selected those that applied, such as 'taste changes', 'lack of appetite', etc. They then rated their selected symptoms on a scale of 0 to 4 (not bothersome to extremely bothersome) and prioritized their needs for symptom management support on a scale of 0 to 10 (not important to receive support to extremely important • A linear mixed-effects model methodology, which accounts for both the correlation between the repeated measurements across times within each subject and the variability between the subjects, was applied to compare the trends over time between

Study ID	Method	Patient characteristics	Interventions	Results	Critical appraisal of study quality
					the two groups on the outcome variables (symptom distress and patient need for symptom management support). Symptom distress was defined as the sum of individual distress scores. Patients' self-reported need for symptom management support was defined by the priority scores for support that patients had assigned to their identified problem categories
Sarna 1998 [15]	• Design: RCT • Funding/CoI: public funding; CoI not reported on • Setting: multicentre, United States • Sample size: N=48 • Duration: not reported; follow-up: 6 months	• Eligibility criteria: patients within 2-3 months of the diagnosis of advanced lung cancer (stage III-IV) • A priori patient characteristics: intervention vs. control ○ Mean age: 62 years ○ Female: 40% ○ Tumour sites: lung	Structured assessment with SDS + HADS + KPS + PFS (N=not reported) vs. Treatment as usual (N=not reported) Structured assessment patients filled in the instruments at approximately 2-3, 3-4, 5-6, 6-7, and 7-8 months after diagnosis. A synopsis was given to the nurse Treatment as usual patients filled in the same instruments, however, their data were not shared with nurses	Distress (mean SDS): 3 months: ±26 vs. ±26 6 months: ± 23 vs. ±29 (Reported in figure only; unlikely to be a significant difference at 6 months because only 21 patients were available at that time) Anxiety: Not reported on over time or between groups Depression: Not reported on over time or between groups Quality of life: Not reported on Unmet needs: Not reported on Communication: Not reported on Medical treatment during follow-up: Not reported on Referrals: Not reported on Proposed/wished/received care:	Level of evidence: high risk of bias; B (EBRO) • Unclear risk of selection bias, high risk of attrition bias, high risk of selective reporting • 27/48 patients dropped out: 10 died, 17 because of increasing physical and emotional distress

Study ID	Method	Patient characteristics	Interventions	Results	Critical appraisal of study quality
				Not reported on	
Velikova 2004 [16, 17]	• Design: RCT • Funding/CoI: public funding; none to report • Setting: single centre, United Kingdom • Sample size: N=286 • Duration: Jan 200-Jul 2001; follow-up: 6 months	• Eligibility criteria: attending the Leeds Cancer Centre Medical Oncology Clinic if commencing treatment • A priori patient characteristics: intervention vs. control ○ Mean age: 55.1 vs. 54.8 vs. 54.7 ○ Female: 75% vs. 70% vs. 74% ○ Tumour sites: breast, gynaecological, renal, bladder, sarcoma, melanoma and other ○ Metastasised disease: 83% vs. 77% vs. 88%	Touch-screen EORTC QLQ-C30 + HADS + feedback of results as a graphic printout to physicians (N=144) vs. Completion of EORTC QLQ-C30 + HADS on touch-screen computer, but no feedback to physicians + TAU (N=70) Treatment as usual (no touch-screen measurement of HRQL before clinic encounters) (N=72) Screening would be done at each visit, so several screens per patient	Distress: Not reported on Anxiety: Not reported on Depression: Not reported on Quality of life (FACT-G): Intervention vs. TAU: 8.01 (95%CI: 2.37 to 13.64; p=0.006) Intervention vs. attention-control: 0.76 (-6.85 to 5.32; p=0.80) The same pattern of results, with main differences between the intervention and TAU arms, but not between intervention and attention-control arms, was observed for physical well-being and functional well-being (data not given but depicted in figure). The emotional well-being of the intervention group patients was better than the control (p=0.008), not different to the attention-control (p=0 .43). No between-group differences were seen in social or family well-being Clinically significant improvement (≥7 points): 40% vs. 32% vs. 24% (Intervention vs. attention-control and TAU groups, p=0.001; intervention and attention-control vs. TAU, p=0.003, using ordinal regression, controlling for baseline FACT-G, performance status, and time on study Unmet needs: Not reported on Communication: ´The number of EORTC QLQ-C30 symptoms mentioned during the encounters was higher in the intervention group in comparison with the control group (p=0.03). More frequent discussion of chronic nonspecific symptoms (difficulty sleeping, lack of appetite, and fatigue) was observed, without prolonging the encounters. As	Level of evidence: high risk of bias; B (EBRO) • Unclear risk of selection bias, high risk of performance bias, high risk of attrition bias • High drop-out rate of around 30% for all groups, for similar reasons and mainly because care was transferred to another hospital or death • audio-taped encounters were submitted to a basic content analysis. Coding was performed directly from the audio tapes by three raters, blinded to patient identity

Study ID	Method	Patient characteristics	Interventions	Results	Critical appraisal of study quality
				expected, there was no between-group difference in the number of other symptoms discussed (p=0.81), suggesting that it was still possible to cover patient and disease-specific problems´ MCQ-communication: ´Patients in the intervention group rated their 'Communication' with doctors significantly better than the control group (p=0.03), but not different from the attention-control group (p = 0.16).´ (Actual data not given, depicted in a graph) <u>Medical treatment during follow-up</u>: Not reported on <u>Referrals</u>: Not reported on <u>Proposed/wished/received care</u>: Not reported on	

Abbreviations: BDI: Beck depression inventory; CI: confidence interval; CNQ-SF: Cancer Needs Questionnaire–short form; CoI: conflict of interest; EORTC-QoLQ: European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire; ESRA-C: Electronic Self-Report Assessment–Cancer; FACT-G: Functional Assessment of Cancer Therapy-General; FLIC: Functional Living Index-Cancer; GHQ-12: Goldberg's General Health Questionnaire-12 version; HADS: Hospital Anxiety and Depression Scale; KPS: Karnofsky Performance Status; MCQ: Medical Care Questionnaire; MOS: Medical Outcomes Study; NNT: number needed to treat; ns: non-significant; PFS: Physical Functioning Scale; POMS: Profile of Moods State; POMS-17 NEG: Profile of Mood States-17 negative affect items; PSI: psychiatric symptom index; PSQ-III: Patient Satisfaction Questionnaire-III; PSSCAN: Psychological Scan for Cancer; QoL: quality of life; RCT: randomised controlled trial; RT: radiotherapy; SD: standard deviation; SDS: Symptom Distress Scale; SIPP: Screening Inventory of Psychosocial Problems

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Uitgangsvraag 4.1 Evidence based

Wat is er bekend over het systematisch signaleren van klachten/detecteren behoefte zorg bij volwassen kankerpatiënten in de eerste lijn?

Uitgangsvraag 4.2 evidence based

Wat zijn de belemmerende en bevorderende factoren voor het systematisch signaleren van klachten/detecteren behoefte zorg bij volwassen kankerpatiënten in de eerste lijn?

Primaire studies

Study ID	Method	Patient characteristics	Interventions & variables	Results	Study assessment and authors´s conclusions
Geelen 2011 [2]	• Study type: qualitative study (focus Group discussions and interviews) • Study aim: what is the view of GPs on care for cancer patients in a chronic phase, what care do they offer, what are the limitations? Do they see the role of the GP as a coordinating role? Setting: the Netherlands • Duration: Sept 2008-Apr 2010 • Participants: 15 GPs(4 online focus group discussion, 11 interviews)	• Not applicable	• Not applicable	• ´Onze analyse maakt duidelijk dat huisartsen, tegen de achtergrond van de grote populatie chronische patiënten in hun praktijk, patiënten die een behandeling voor kanker hebben doorstaan geen bijzondere positie toekennen. Ze onderstrepen dat ze deze patiënten, net als veel andere (chronische) patiënten, 'gewone' zorg willen bieden. Voor huisartsen houdt dat in dat ze vraaggestuurd werken: de patiënt moet zelf het initiatief nemen en zelf om hulp vragen. Initiatiefrijke patiënten, die in staat zijn hun problemen helder te presenteren, hebben dus meer kans om de juiste (dat wil zeggen: holistische) zorg te krijgen van de huisarts. Niet alle huisartsen vinden dit overigens een goede zaak. Ze betwijfelen of de lichamelijke, maar ook psychische en sociale problemen waarmee mensen na kanker vaak nog langdurig kampen in de spreekkamer wel voldoende op tafel komen. De beperkte tijd in een consult en de organisatie van hun werk maakt het echter moeilijk om proactief te exploreren welke zorg iemand nodig heeft. Huisartsen verwijzen deze patiënten slechts beperkt door naar andere hulpverleners, en de huidige organisatie van de huisartsenpraktijk voorziet niet in structurele nazorg aan patiënten die een kankerbehandeling ondergaan hebben. Voor een deel komt dit doordat huisartsen geneigd zijn de 'eigen kracht' van patiënten te benadrukken […]´	• Recruitment GPs via Comprehensive Cancer Centers and professional organisations • Small sample • Conclusions authors: ○ ´Huisartsen zijn niet geneigd om patiënten die een kankerbehandeling hebben ondergaan een aparte positie toe te kennen ○ Zij zien niet duidelijk voor zich hoe de nazorg aan deze gevarieerde patiëntengroep gestructureerd zou moeten worden ○ Zij hebben ook te weinig inzicht in wat andere eerstelijnszorgverleners daaraan zouden kunnen bijdragen´

Study ID	Method	Patient characteristics	Interventions & variables	Results	Study assessment and authors´s conclusions
				• Demedicalising symptoms and gateway function were also mentioned as reasons for restricted referral • GPs ´zien niet heel duidelijk hoe een gestructureerde follow-up van kanker in de chronische fase er uit zou moeten zien. De grote verscheidenheid in het beloop van de verschillende vormen van de aandoening maakt het moeilijk een standaardvorm voor de follow-up te ontwikkelen zoals de speciale spreekuren of zorgprogramma's voor bijvoorbeeld patiënten met diabetes, COPD of hartfalen. […] Ze zien ook alternatieven voor de inzet van de huisarts. Een gespecialiseerde verpleegkundige bijvoorbeeld, omdat patiënten volgens hen positieve ervaringen hebben met oncologieverpleegkundigen in het ziekenhuis. Enkelen zien winst in het inzetten van een nurse practitioner voor de niet-medische zorg. De medische zorg, vraaggestuurd of gestructureerd, zal altijd de verantwoordelijkheid van de arts blijven.´	
Goonewardene 2013 [3]	• Study type: descriptive study (abstract) • Study aim: investigating general practitioners views of a prostate cancer survival ship programme • Setting: single centre, United Kingdom • Duration: from 2009 onwards • Participants: general practioners (number not reported)	• Not applicable	• Prostate cancer patients are offered entry to a Survivorship programme. Patients must have survived 2 years after radical prostatectomy, with an unrecordable PSA reading, 3 years after external beam radiotherapy with no metabolic relapse, or brachytherapy with no metabolic relapse. Recurrence is monitored by PSA measurements. After being discharged their details, including PSA measurements, are entered into a password-	• ´Among general practitioners low confidence levels in managing relapsing/hormone resistant breast and prostate cancer, and in the management of side effects were detected. Half of the practitioners were not fully informed about the survivorship programme, which is designed to remove this burden of care from general practice, and many had misconceptions about the programme: 25% thought it was a programme to empower patients who are cured, and 15% thought it simply offered a holistic approach´	• Available in abstract form only

Study ID	Method	Patient characteristics	Interventions & variables	Results	Study assessment and authors´s conclusions
			protected database by a specialist nurse, who acts as the patients' keyworker. This database can generate alerts if the PSA is elevated so that patients can be brought back to the clinic by the specialist nurse who can also respond to symptoms or signs of recurrence, adverse effects of treatment or a patient's request		
Mikkelsen 2009 [4]	• Study type: cross-sectional cohort study • Study aim: to assess cancer survivors' perceived need for physical and psychosocial rehabilitation, whether these needs have been presented to and discussed with their general practitioner • Setting: Denmark • Duration: 2006 • Participants: 534 eligible patients, identified from the counties Hospital Discharge Registry	• Cohort of cancer survivors approximately 15 months after diagnosis. All new, diagnosed cancer patients between 18 and 75 years of age, admitted to hospital between 12 and 18 months before October 8, 2006 • Excluded: patients with non-melanoma	• The questionnaire consisted of an ad hoc questionnaire on rehabilitation needs and two validated questionnaires, the SF-12 and the Research and Treatment of Cancer quality of life questionnaire, the QLQ C-30 version 3	• Physical aspects had been discussed with the GP by 66.9% (range 58.1–78.6% depending on cancer type) • Mental aspects had been discussed with the GP by 48.0% of the patients with much variation related to cancer type (32.3–57.1%) • Social problems were less often discussed with GP • At discharge, a rehabilitation plan had been made for 80 (23.7%) of the patients • GPs had initiated rehabilitation after discharge from hospital for 50 (15.2%) of the patients. • Good physical and mental condition and low confidence in the GP were associated with no contact to the GP after hospital discharge	• Response: 66.1% of eligible patients

Study ID	Method	Patient characteristics	Interventions & variables	Results	Study assessment and authors´s conclusions
		skin cancers, cervical carcinoma in situ, multiple myelomas and leukaemia; perceived to be cured at this time point, had a relapse, did not understand the Danish language according to their general practitioner • Patient characteristics: 63% women; mean age 63 years;			
Smith 2011 [5]	• Study type: survey • Study aim: assessing the perceptions of primary care physicians about the care of breast cancer survivors after completion of active treatment and their personal preferences for resources providing information about breast cancer • Setting: Canada • Duration: June 2007-Aug 2008	• 61% of GPs had more than 10 survivors in their practice; 28% 6–10 survivors; and 11% 1–5 survivors in their practice	• 1-page, 31-item checkbox and open- answer generic questionnaire mailed to 1000 primary care physicians caring for survivors of breast cancer	• self-rated good or adequate level of confidence in counseling for: ○ screening for recurrence:99% ○ Anxiety for recurrence: 97% ○ Treatment-related osteoporosis: 92% ○ Nutrition and exercise: 89% ○ Treatment-induced menopause: 88% ○ Adjuvant hormone therapy: 85% ○ Family counseling: 76% ○ Lymphedema: 76% ○ Sex and body image: 74%	• Response 59%

Study ID	Method	Patient characteristics	Interventions & variables	Results	Study assessment and authors´s conclusions
	• Participants: 1000 GPs				
Webber 2013 [6]	• Study type: cross-sectional survey (abstract) • Study aim: to explore the unmet needs of adult cancer survivors and their levels of comfort in addressing issues with oncologists and GPs • Setting: multicenter, Australia • Duration: not reported • Participants:228 responders	• Adult cancer survivors 4 years from diagnosis from 6 oncology units • Mean age of 59.3 years • 71.5% female • Primary cancers: breast (71.5%), colorectal (13.9%), prostate (4.5%) and ovarian (2.2%)	• Questionnaire (unspecified)	• Unmet needs: ○ Information about late effects (50.3%) ○ Managing fatigue (41.7 %) ○ Genetic risk to family (34.7%) ○ Reassurance (32.0 %) ○ Diet (31.4 %) • Median number of unmet needs: 4 (range 0-23) • On multivariate analysis higher education (p=0.04) remained independently associated with greater unmet needs • Preferred provider for addressing needs (%):	• Available as abstract only • 50.5% response

Study ID	Method	Patient characteristics	Interventions & variables	Results	Study assessment and authors´s conclusions

Issue	Oncologist	GP	Neither
Cancer treatment	89.9	40.1	5.5
Follow-up care	80.8	42.4	9.1
Frequency of check-ups	87.8	28.5	6.8
Late effects	77.8	35.1	12.5
General health	6.4	94.9	3.7
Lifestyle behaviors	26.1	62.5	28.1
Fatigue	35.0	61.2	24.0
Finances	4.3	11.5	85.5
Education	3.1	12.5	84.4
Employment	19.7	22.8	65.2
Psychological support	18.4	36.3	54.8
Exercise	16.4	41.3	52.5
Diet	16.1	42.6	51.1

Abbreviations: GP: general practitioner

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De huisarts: Spil in de nazorg voor patienten met kanker? Huisarts en Wetenschap, 2011. **54**(11): p. 586-590.
3. Goonewardene, S.S., et al., *The Worcestershire prostate cancer survivorship programme: A new concept for holistic long term care and follow-up.* BJU Int, 2014. **113**: p. 116-117.
4. Mikkelsen, T., et al., *Cancer survivors' rehabilitation needs in a primary health care context.* Fam Pract, 2009. **26**(3): p. 221-30.
5. Smith, S.L., et al., *Caring for survivors of breast cancer: perspective of the primary care physician.* Curr Oncol, 2011. **18**(5): p. e218-26.
6. Webber, K., et al., *The unmet needs of cancer survivors and their preferences for discussing them with oncologists and general practitioners (GPs).* Journal of Clinical Oncology, 2013. **1)**.

Uitgangsvraag 5.1: Welke (screenings)instrumenten zijn er voor het signaleren van klachten/detecteren behoefte zorg tijdens en na afronding van de in opzet curatieve behandeling en in de (ziekte- en symptoomgerichte) palliatieve fase bij volwassen kankerpatiënten?

1 DIAGNOSIS

1.1 PRIMARY STUDIES

I Study ID	II Method	III Patient characteristics	IV Intervention(s)	V Results	VII Critical appraisal of study quality
• (Admiraal, Reyners, & Hoekstra-Weebers, 2013)	• Design: cross sectional • Source of funding: not reported • Setting: 19 hospitals in the North-Eastern CCCN region • Sample size: varying between 1165 and 1340 in analyses) • Duration: not reported	Eligibility criteria: (1) patients who where aware of their cancer diagnosis and treatment plan (2) 'wait and see' condition (prostate cancer patients only), under active treatment, or visited the hospital for FU after treatment completion (3) ≥18 years (4) Physically and cognitively able to complete the questionnaire (5) Sufficiently fluent in Dutch Patient Characteristics • Mean age 61 years; 37% men; mean time since diagnosis 2.0 years,	• Index test (s): Dutch Distress Thermometer / problemlist • Reference standard HADS	• AUC: ○ Breast 0.82 (95% CI 0.77-0.86): cut off 5 ○ Digestive, gynaecologic, head/neck ranging between 0.72 and 0.84, cut off 5 ○ Prostate: 0.77, (95% CI 0.62-0.92), cut off 4 ○ Sarcoma, bone: 0.87 (95% CI 0.76-0.92), cut off 4 ○ Lung: 0.80 (95% CI 0.66-0.95), cut off 5 N completing (DT + HADS) / Cutoff point / Sensitivity / Specificity / LR+ / PPV / NPV Breast 488 5 0.85 0.66 2.48 0.32 0.96 Prostate 147 4 0.86 0.76 3.56 0.28 0.98 Digestive 131 5 0.71 0.65 2.00 0.43 0.86 Lung 78 4 0.87 0.52 1.82 0.33 0.94 Gynecologic 73 5 0.92 0.69 2.94 0.37 0.98 Head/neck 72 5 0.77 0.63 2.06 0.35 0.91 Sarcoma/bone 49 4 1.00 0.65 2.86 0.42 1.00	• Risk of bias: high • Response rate 51 % • Reference standard only measuring anxiety and depression

		treatment phase: 2% wait and see, 44% under active treatment, 54% FU			
• (Wells-Di Gregorio et al., 2013)	• Design: validation study • Source of funding: not described • Setting: clinical, Center for Palliative Care • Sample size: 596 • Duration: Jan 2010-Dec 2011	• Eligibility criteria: oncology patients referred for the Center for Palliative Care • Patient characteristics: 52% males, 85% Caucasian, head and neck cancer (27%), hematologic cancer (13%), gynaecologic cancer • (9%), lung cancer (8%), breast cancer (8%), brain cancer(7%), and colorectal cancer (6%), recurrent (11%) or metastatic disease (40%), local disease (21%) remission (25%) • Prevalence of distress (various domains): 14.3% - 65.6% (for pain)	• Index test(s): James SCS • Reference standard: BPI, Center for Epidemiologic Studies Depression Scale, DSM-IV, DT, ISI, The State-Trait Anxiety Inventory-State version	<table><tr><th></th><th colspan="3">DSM-IV Major depressive discorder</th><th colspan="3">DSM-IV generalized anxiety disorder</th></tr><tr><th>SCS item</th><th>Sen</th><th>Spe</th><th>Chi2</th><th>Sen</th><th>Spe</th><th>Chi2</th></tr><tr><td>Feeling down≥moderate distress</td><td>51.2</td><td>90.1</td><td>41.0**</td><td>—</td><td>—</td><td>—</td></tr><tr><td>Uncertainty≥moderate distress</td><td>—</td><td>—</td><td>—</td><td>41.4</td><td>86.9</td><td>21.1**</td></tr><tr><td>Distress Thermomter≥4</td><td>75.6</td><td>45.1</td><td>8.5*</td><td>77.3</td><td>45.4</td><td>10.8*</td></tr></table>*p<0.01 **p<0.001 Results support use of the James SCS to quickly detect the most frequent and distressing symptoms and concerns of cancer patients.	• Risk of bias: low • response rate was 100% • thorough analysis • valid reference standards • Center for Palliative Care
• (Lowery et al., 2012)	• Design: validation study • Source of funding: not reported • Setting: multispecialty or infusion clinics UC	• Eligibility criteria: cancer diagnosis, at least 18 years of age, attending an outpatient appointment ability to give informed consent • Patient characteristics:	• Index test(s): CaNDI • Reference standards: HADS, FACT-G, BSI, request to speak with a staff member	• The internal consistency reliability coefficients for the CaNDI total score were α=0.91 for both the full and retest samples at time 1 and α=0.92 for the retest administration.	• Risk of bias: low • response rate was 100% • valid reference standards

	San Diego Moores Cancer Center • Sample size: 100 • Duration: not reported	male 27%. Multispecialty clinic age<40 years 12%, 40-60 52% >60 years 36%. Infusion clinic <40 years 12% 40-60 45% > 60 years 43%		**Table 4.** CaNDI subscale score sensitivity and specificity compared to HADS caseness ($N = 100$) **Depression subscale cutoff** / **Sensitivity** / **Specificity** 4 / 0.88 / 0.22 5 / 0.88 / 0.54 6 / 0.83 / 0.74 7 / 0.75 / 0.84 8 / 0.67 / 0.93 9 / 0.54 / 0.99 10 / 0.38 / 0.99 Anxiety subscale cutoff 2 / 0.88 / 0.49 3 / 0.80 / 0.75 4 / 0.52 / 0.93 5 / 0.44 / 0.99 6 / 0.20 / 1.00 **Table 5.** Sensitivity and specificity of CaNDI subscale scores relative to requests to speak with a staff member ($N = 100$) **Depression subscale cutoff** / **Sensitivity** / **Specificity** 5 / 0.93 / 0.50 6 / 0.93 / 0.69 7 / 0.86 / 0.79 8 / 0.71 / 0.77 9 / 0.57 / 0.93 10 / 0.29 / 0.93 Anxiety subscale cutoff 2 / 1.00 / 0.43 3 / 0.75 / 0.64 4 / 0.63 / 0.86 5 / 0.63 / 0.92 6 / 0.50 / 0.99	

<table>
<tr>
<td>• (Miller et al., 2013)</td>
<td>• Design: validation study
• Source of funding: grants from Genetech, Eli Lilly, and company Foundation and Pfizer
• Setting: cancer survivors from 14 Cancer Support Community (CSC) affiliate sites US.
• Sample size: 319
• Duration : Sept-Dec 2010</td>
<td>• Eligibility criteria: English-speaking cancer outpatients 18 years of age and over, who were in treatment or follow-up
• Patient characteristics : age range 28-87 years, 17% <50, 84% female, most recent cancer diagnosis, breast 45%, blood 12%, other 16%, gynecologic 9%, colorectal, 5%, Lung 5%, Prostate 3%, multiple reported 7%</td>
<td>• Index test(s): Distress Screener (DS)
• Reference standard: FACT_G. CES-D, DT</td>
<td>• Internal reliability: Cronbach’s coefficient: 0.91 for the 36 items on the DS
• Concurrent validity: :DS summary score was negatively correlated with FACT-G: R^2 =0.58 (P<0.001) and positively correlated with CES-D : R^2 = 0.48; p<0.001 and DT R^2= 0.35 ;p<0.001
• AUC was 0.80 using the DT cut off score ≥4 as the criterion, and the AUC was 0.83 using the CES-D cut off score.
• Using DT as the criterion a count score >=8 : sens 0.65 and spec 0.82.
• If a cut off of 4 was used for the count of items rated 3 or higher, the sens 0.85 spec 0.52
• Mean (±SD) number of screening items rated ≥ 4 was significantly higher among those who were distressed (DT>4; 2.9±3.5, n=141) compared with those who were not distressed (0.6±1.5, n=151).</td>
<td>• Risk of bias: low</td>
</tr>
<tr>
<td>• (Braeken, Lechner, Houben, Van Gils, & Kempen, 2011)</td>
<td>• Design: cross sectional
• Source of funding: not reported
• Setting: MAASTRO radiation clinic, Maastricht NL
• Sample size: 289 / 76 for interview
• Duration: Jan2006 - March 2008</td>
<td>• Eligibility criteria: received radiotherapy treatment in the study setting, diagnosis of lung, breast, prostate or gynaecological cancer, sufficient comprehension of the Dutch language, aged 18 years or over, and able to provide written informed consent for inclusion in the study.
• Patient characteristics:</td>
<td>• Index test(s): SIPP
• Reference standard: HADS, Mental Adjustment to
• Cancer scale, additional structured clinical interview for DSM IV (SCID-I) with 76 patients by blinded interviewer</td>
<td><table><tr><td>SIPP (number of items, theoretical score range)</td><td>Cronbach’s α</td></tr><tr><td>Physical complaints (7,0-14)</td><td>0.79</td></tr><tr><td>Psychological complaints (10, 0-20)</td><td>0.91</td></tr><tr><td>Social problems (4, 0-8)</td><td>0.51</td></tr><tr><td>Total score (21, 0-42)</td><td>0.91</td></tr></table></td>
<td>• Risk of bias: high
• Response rate was only 32.5% (possibly risk of patient selection)
• not all patients filled out the reference standard
• only prostate cancer patients receiving RT were included</td>
</tr>
</table>

		mean age: 67.8 (range 23-91), 86.2% males, cancer diagnosis: Prostate 70.6%, Lung 20.1%, Breast 2.8%, Gynaecological 6.5%, WHO performance scale 0 for 67.1 of the patients, married or living with a partner (84.8%), had an elementary level of education (43.9%) • Prevalence of distress "yes" (various domains): 2.4% -17.6% (for fatigue)		Cut-off points SIPP for clinical distress symptoms Physical complaints / Sen (%) / Spe (%) 0/1 100.0 20.3 1/2 100.0 35.9 2/3 100.0 50.0 3/4 100.0 62.5 4/5 100.0 71.9 **5/6 100.0 79.7** 6/7 85.7 87.5 7/8 57.1 90.6 8/9 42.9 92.2 9/10 28.6 93.7 10/11 28.6 95.3 11/12 14.3 98.4 Psychological complaints 0/1 100.0 15.6 1/2 100.0 31.2 2/3 100.0 53.1 3/4 100.0 65.6 4/5 100.0 71.9 5/6 100.0 73.4 6/7 100.0 84.4 7/9 100.0 85.9 **9/10 100.0 89.1** 10/11 85.7 92.2 11/12 85.7 96.9 12/13 71.4 96.9 13/15 57.1 98.4 15/18 57.1 100.0 18/20 14.3 100.0 AUC for clinical symptoms (highly distressed) and for subclinical symptoms (moderately distressed) was 0.92 (95% CI 0.85-0.92) and 0.83 (95% CI 0.73-0.92) respectively, when the SIPP physical complaints subscale was used. AUC for clinical symptoms (highly distressed) and for subclinical symptoms (moderately distressed) was 0.98 (95% CI 0.94-1.01) and 0.93 (95% CI 0.86-0.99) respectively, when the SIPP psychological problems subscale was used.	

• (Lambert et al., 2014)	• Secondary analysis of data from a previous cross sectional study • Source of funding: NHMRC Research Fellowship • Clinical: Calvary Mater Newcastle hospital, Australia • 377 (of 1707 eligible) patients: 340 were included in this analysis • April-May 2005	• Eligibility criteria: adults with malignant disease in medical oncology, surgical oncology, radiation oncology, and haematology, sufficient English language skills, attending non-surgical oncology and haematology outpatient clinics, and well enough to participate • Patient characteristics: mean age 60 years (SD = 12, range 18–88 years), 52 % male, 74 % married or in a de facto relationship. 49% was retired 2/3 participants were receiving treatment at the time of the study, and the three most common cancer diagnoses were haematological (24 %), breast (24 %) or urological cancer (15 %) • Prevalence of distress: 47.4% (DT≥4)	• DT • HADS-Total • HADS Anxiety (HADS-A) • HADS Depression (HADS-A)	<u>DT versus HADS-A</u> Sensitivity Cut off 4 82.1% 5 74,4% 6 57.3% 7 46.2% Clinical cut off score = 7 Specificity Cut off 4 71,2% 5 76.6% 6 86.0% 7 91.9% <u>DT versus HADS-D</u> Sensitivity Cut off 4 80.0% 5 72.0% 6 58.7% 7 46.7% Clinical cut off score = 8 Specificity Cut off 4 61.9% 5 67.5% 6 79.2% 7 85.7%	• Risk of bias: high • The use of the HADS as a reference standard is questionable • Low response rate of 23% (possibly risk of patient selection), the DT cut off scores are influenced by the prevalence of the condition of the sample.

• (Lazenby, Dixon, Bai, & McCorkle, 2014)	• Cross sectional secondary analysis of RCT • Source of funding: NIH/NIHR grant • Clinical • Sample size: 123 patients • Duration not mentioned	• Eligibility criteria: 1) within 30 days of a definitive primary diagnosis of Stage 3 or 4 GI (including pancreatic and esophageal), gynecological, head-and-neck, or lung cancers; 2) post-surgical (including biopsies) with a physician's order for ongoing oncologic treatment; 3) life expectancy of at least six months as confirmed by a medical oncologist; 4) age of 21 years or older; and 5) living within the State of Connecticut. 6) Informed consent. • Patient characteristics: 59.9 (SD 12.9) years, 56.9% were female. All had Stage 3 or 4 cancers (40% gastrointestinal, 19% gynaecologic, 20% head and neck, 21% lung). • The mean DT score was 3.9 (SD 2.7)/10; and 56 (43%) were depressed as measured by the PHQ-9 ≥5.	• Index test(s): DT • PHQ-9	Positive screens on PHQ-9 ≥ 5 DT Cut off sensitivity BI ≥0 100 (93–100) ≥1 98 (91–99) ≥2 96 (88–99) ≥3 86 (74–93) ≥4 73 (60–83) ≥5 57 (44–69) ≥6 43 (31–56) ≥7 29 (19–41) ≥8 21 (13–34) ≥9 10 (5–20) ≥10 5 (2–14) Negative screens on PHQ-9 ≥ 5 DT Cut off specificity BI ≥0 0 ≥1 22 (14–34) ≥2 36 (25–46) ≥3 46 (34–59) ≥4 63 (50–74) ≥5 76 (64–85) ≥6 87 (76–93) ≥7 90 (79–95) ≥8 96 (87–99) ≥9 100 (93–100) ≥10 100 (93–100) Conclusion: the optimal DT threshold for identifying possible cases of depression is ≥ 2. AUC=0.752	• Risk of bias: high • patients were selected based on willingness to participate, which may have excluded the patients with higher risk for depression. This may have lead to underestimation of diagnostic accuracy. • PHQ-9 measures depression

• (King, Bell, Costa, Butow, & Oh, 2014)	• Design: secondary analysis or RCT • Source of funding: • Australian Government through Cancer Australia, NHMRC Research Fellowship. • Setting: clinical • Sample size: 162 • Duration: July 2006-may 2008	• Eligibility criteria: malignancy of any stage, were aged ‡18 years and had an expected survival length of >12 months, informed consent • Exclusion: diagnosis of a major medical or psychiatric disorder (other than cancer), had a history of epilepsy, brain metastasis, delirium or dementia, had medical contraindications for exercise or were already practicing Qigong (intervention of RCT) • Patient characteristics: mean age 60 (31-86), breast cancer (34%), colorectal cancer (12%), lung cancer (8.7%), prostate cancer (8.7%), other (33,3%).	• Index test(s) / Reference standard:): EORTC and FACT-G	• FACT-G total score was more efficient than QLQ-C30 global scale for detecting change within the intervention arm [RE 5 0.31 (0.083, 0.69)] and comparing change between trial arms [RE 5 0.17 (0.009, 0.58)]. • In the social domain, the QLQ-C30 scale was more responsive [DR 0.28 (0.024, 0.54)] and more efficient within arm only [RE 5.25 (1.21, 232.26)]. • In the physical, functional/role, and emotional domains, neither questionnaire was more responsive or efficient.	• Risk of bias: UNCLEAR • response rate was only 18%, and patients with a diagnosis of a major medical or psychiatric disorder were excluded. This may have lead to underestimation of diagnostic accuracy. • EORTC and FACT-G were compared
• (Hinz et al., 2012)	• Design: validation study in a sample of cancer patients and a sample of the general population • Source of funding: unknown • Setting: patient	• Eligibility criteria: Cancer patients:presence of tumour, age 18 years and above, sufficient physical and mental stability, and sufficient command of German language • Patient characteristics: mean age: 60.3	• Index test(s): EORTC QLQ C30 alternative scoring (function, symptom and total) • Reference standard: HADS-D and Multidimensional Fatigue Questionnaire (MFI)	<u>Cronbach's alpha values:</u> • <u>cancer patients</u> 0.89 (function), 0.87 (symptom), 0.94 (total) 0.90 (two-item QoL). • <u>general population</u> 0.91 (function), 0.87 (symptom), 0.95 (total) 0.89 (two-item QoL). <u>Discriminant validity between patients and controls:</u>	• Risk of bias: high • Main reasons for non-participation were current treatment, relocation or discharge, bad physical or mental state, and refusal, which may

<table>
<tr>
<td></td>
<td>sample: cancer patients University Hospital Leipzig, Germany / representative sample general population
• Sample size: 1529 cancer patients and 1185 sample general population
• Duration: controls: 1998, patients: 2002-2004</td>
<td>years, males: 59.2%, time since diagnosis longer than 1 month: 52.5%, survival time longer than one year: 82.8%
• breast (11.3%), other gynaecological (12.6%), prostate (18.8%), other urological, (10.5%), lung (3.5%), colon (4.1%), other gastrointestinal, (19.2%), head/neck (7.8%), brain (4.6%) and others (7.7%)
• Mean Score EORTC QoL: patients 55.3 (SD 24.7); controls 66.3 (SD 22.0)</td>
<td></td>
<td>effect size of the two-item QoL scale is only 0.50,
the newly built sum scales between 0.74 and 0.87

<u>Convergent validity with reference standard:</u>
The correlations between the new scales function and total are generally higher (maximally -0.76, for EORTC QLQ C30 Total vs. MFI) than those of the two-item QoL scale (maximally -0.65, for EORTC QLQ C30 Total vs. MFI).

The calculation of sum scores provides useful information for clinicians who are interested in one generalising score of quality of life</td>
<td>have introduced selection bias
• HADS measures anxiety and depression, MFI measures fatigue</td>
</tr>
<tr>
<td>• (Snyder et al., 2010)</td>
<td>• Design: cross-sectional
• Source of funding: Mentored Research Scholar Grant American Cancer Soceity, Ageon International Fellowship in Oncology
• Setting: clinical, patients of 7 medical oncologists
• Sample</td>
<td><u>Eligibility criteria:</u>
(1) diagnosis of breast, prostate, or lung cancer at any stage,
(2) aged 18 or older,
(3) currently undergoing treatment with chemotherapy, radiation therapy, hormonal therapy, biologic therapy, or therapy as part of a clinical trial,
(4) physically and cognitively able to complete the questionnaire,
(5) able to read and write in English
(6) able and willing to provide oral informed consent</td>
<td>• Index test(s): EORTC QLQ30
• Reference standard: SCNS</td>
<td>
<table>
<tr><th>EORTC scale</th><th>SCNS item</th><th>Cut-off</th><th>Sensitivity</th><th>Specificity</th><th>PPV</th><th>NPV</th></tr>
<tr><td>Physical fynction</td><td>Work around the home</td><td>80
90</td><td>.65
.85</td><td>.83
.58</td><td>.55
.39</td><td>.89
.92</td></tr>
<tr><td>Role function</td><td>Work around the home</td><td>80
90</td><td>.69
.85</td><td>.79
.69</td><td>.50
.46</td><td>.89
.94</td></tr>
<tr><td>Emotional funtioning</td><td>Feelings of sadness</td><td>90
100</td><td>.89
.94</td><td>.53
.35</td><td>.48
.41</td><td>.91
.93</td></tr>
<tr><td>Global health/QO</td><td>Feeling unwell a lot</td><td>80
90</td><td>.89
.94</td><td>.58
.31</td><td>.50
.39</td><td>.91
.92</td></tr>
<tr><td>Pain</td><td>Pain</td><td>20
10</td><td>.66
.91</td><td>.84
.66</td><td>.64
.54</td><td>.85
.95</td></tr>
<tr><td>Fatigue</td><td>Lack of energy/tiredn</td><td>20
10</td><td>.91
.96</td><td>.55
.25</td><td>.68
.57</td><td>.86
.88</td></tr>
</table>
Using a cut-off of 80:
Sensitivity: 0.65
Specificity: 0.83
PPV: 0.55
NPV: 0.89

Using a cut-off of 90:
Sensitivity: 0.85</td>
<td>• Risk of bias: low
• response rate was high: 91%, reasons for nonparticipation are described
• thorough analysis
• valid reference standard</td>
</tr>
</table>

	size: 117 • Duration: Jan-May 2006	• Patient characteristics: mean age 61 years; 51% men; 77% white, mixed cancers: Breast 43.1%, prostate 41.1%, lung 15.5%, all stages: early: 35.3%, locoregional: 14.7%, metastatic:50% • Patients had good performance status, with 95% having ECOG ratings of 0 or 1.		Specificity: 0.58 PPV: 0.39 NPV: 0.92	
• (Snyder et al., 2015)	• Design: secondary analysis of data from a cluster randomized controlled trial • Source of funding: analysis was funded by the American Cancer Society. The original data collection was supported by the Canadian Health Services Research Foundation. • Setting: 28	<u>Eligibility criteria:</u> (1) newly diagnosed breast and colorectal cancer patients within 7 days of their surgery, (2) no previous of concomitant malignancies (3) legally able to give IC (4) ≥ 18 years (5) able to speak and read in English • Patient characteristics: mean age 60 years; 20% men; breast 63%, colorectal 37% • 57% had a college degree, 62% were married	• Index test(s): EORTC QLQ30 • Reference standard: SCNS	*Physical Function AUC 0.69* Using a cut-off of 80: Using a cut off of 90 Sensitivity: 0.79 0.91 Specificity: 0.51 0.23 PPV: 0.34 0.28 NPV: 0.88 0.89 *Role Function AUC 0.69* Using a cut-off of 80: Using a cut off of 90 Sensitivity: 0.94 0.99 Specificity: 0.32 0.16 PPV: 0.54 0.50 NPV: 0.87 0.94 *Emotional Function AUC 0.79* Using a cut-off of 90: Using a cut off of 100 Sensitivity: 0.92 1.00 Specificity: 0.43 0.23 PPV: 0.38 0.32 NPV: 0.94 1.00 *Global Health/QOL AUC 0.72* Using a cut-off of 70: Using a cut off of 80 Sensitivity: 0.96 0.98 Specificity: 0.34 0.24 PPV: 0.32 0.30 NPV: 0.96 0.97	• Risk of bias: low • Secondary analysis of cluster RCT including only breast and colorectal cancer patients within 7 days of their surgery. • Reference standard SCNS-SF34 measures unmet needs in five domains

	surgical clinics, Toronto CA • Sample size: 193 • Duration: not reported			*Pain AUC 0.75* Using a cut-off of 20: Using a cut off of 10 Sensitivity: 0.90 0.95 Specificity: 0.46 0.26 PPV: 0.32 0.26 NPV: 0.95 0.95 *Fatigue AUC 0.68* Using a cut-off of 30: Using a cut off of 20 Sensitivity: 0.94 0.99 Specificity: 0.32 0.19 PPV: 0.44 0.40 NPV: 0.91 0.96 10 point EORTC QLQ C30 score represent changes in supportive care needs	
• (Jones et al., 2014)	• Design: 2 retrospective cohort studies (secondary analysis) • Source of funding: National Cancer Institute; MD Anderson Cancer Center support, Hawn Foundation • Setting: retrospectively collected from 2 patient cohorts. Data were originally collected in a tertiary cancer center, Houston.	Eligibility criteria: • <u>cohort 1:</u> scheduled to receive chemotherapy, ≥ 18 years of age, able to read and speak English, informed consent • <u>Cohort 2</u>: ≥ 18 years of age, Zubrod performance status ≤ 2, able to write and speak English, informed consent. Exclusion: history of immunodeficiency, using immunosuppressive drugs, having a confirmed psychiatric diagnosis of depression, or receiving psychiatric services. Patient characteristics: <u>Cohort 1</u>: mean age: 59.8 years, 62% males, advanced (stage IIIB or IV) non–small-cell	• Index test(s): MDASI Reference standard: • <u>cohort 1</u>: Beck Depression Inventory-II (BDI-II) • <u>cohort 2</u>:Center for Epidemiologic • Studies Depression Scale (CES-D)	The MDASI single item “sadness”, cut point ≥ 4 (0-10 scale) <u>Cohort 1:</u> • Sensitivity: 72.0% • Specificity: 81.5% • NPV: 95.0%, • PPV: 37.5% <u>Cohort 2:</u> • Sensitivity: 68.0% • Specificity: 91.0% • NPV: 97.0%, • PPV: 42.5%	• Risk of bias: high patients were selected based on willingness to participate, which may have excluded the patients with higher risk for the outcome measure. This may have lead to underestimation of diagnostic accuracy. • patients having a confirmed psychiatric diagnosis of depression, or receiving psychiatric services were excluded. This may have lead to underestimation of diagnostic accuracy.

	Sample size: • cohort 1: 187 patients with advance non-small cell lung cancer whore were recruited to evaluate symptom burden in late stage disease • cohort 2: 281 patients with renal cell carcinoma participating in a RCT expressive writing	lung cancer (NSCLC) Cohort 2:, mean age 58.1, 58.7% males, all stages renal cell carcinoma Prevalence of distress • cohort 1, 13.4% moderate-to-severe depressed mood (BDI-II score ≥ 20 • cohort 2, 8.9% moderate-to severe depressed mood (CES-D score ≥ 27		Moderate-to-Severe Depressive symptoms Assessment — Sensitivity (%) — Specificity (%) Individual item score ≥4 Single item Cohort 1 Sadness 81.5 72.0 Distress 78.4 56.0 Interference with enjoyment of life 66.5 76.0 Interference with mood 78.4 68.0 Cohort 2 Sadness 91.0 68.0 Distress 89.5 72.0 Interference with enjoyment of life 85.9 64.0 Interference with mood 87.4 72.0 Component score ≥19 Multiple item Depressed-mood component Cohort 1 83.0 84.0 Cohort 2 88.9 76.0 The MDASI “sadness” item can serve as a useful initial screen for depressed mood.	• Study is mainly focussed on measuring depression with 1 item of the MDASI

The Brief Pain Inventory (BPI), Eastern Cooperative Oncology Group Performance Status (ECOG PS), European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30), Insomnia Severity Index (ISI), James Supportive Care Screening (SCNS), Sen = sensitivity, spe = specificity, Chi2 = Chi-square, brae (SCID)

Systematic reviews

I Study ID	II Method	III Patient characteristics	IV Intervention(s)	V Results outcomes	VII Critical appraisal of review quality
• (Mitchell, 2010)	• Meta analyse • No financial support reported • Last search date was August 2009 (period 2007-2009) • Searched databases: Pubmed, EMBASE, SCOPUS, Web of knowledge • Included study designs: diagnostic validity studies of tools to identify distress in cancer and palliative settings • Number of included studies: 4 (about the DT)	• Eligibility criteria: tools to identify distress in the cancer and palliative setting, limited to studies measured against interviewed defined distress • Exclusion: non cancer, primary setting • Patient characteristics: not described	• Index test(s): DT / DT and IT • Reference standard: interview defined distress	• Essentially 2 questions (or 2 thermometers) appear to be more accurate than 1. The casefinding ability is given by an AUC2Q of 0.831 and the screening ability AUC2Q of 0.673. • Weighted Sensitivity: DT 78.5% (69.8%–86.1%) / DT and IT 81.3% (74.6% - 90.3%) • Weighted specificity: DT 67.4% (95% CI, 60.1%–74.3%) / DT and IT 82.1% (95% CI, 75.3%-87.3%) • Case-finding ability (AUC+): DT 0.643 / DT and IT 0.734 • Screening ability (AUC-): DT 0.682 / DT and IT 0.730	• Risk of bias: unclear • No information is given about the quality of the original studies, nor about the risk of publication bias. • Statistical analysis of the pooled accuracy measures seem appropriate
• (Ma et al., 2014)	• Meta analyse • No financial support • Last search date was Sept the 20th, 2013 (period 1997-2013) • Searched databases: Pubmed, EMBASE • Included study designs: no restrictions • Number of included studies: 42	• Eligibility criteria: human subjects • Patient characteristics: cancer patients with active treatment, or survivors, or a mix of these groups	• Index test(s): DT • Reference standard: HADS-A, HADS–D, HADS-T, DSM-IV, PDI, BSI-18, GHQ-12, GHQ-30, ICD-10, PHQ-9, SCL-90-R, PSYCH-6	Pooled data, 42 studies, all reference standards AUC 0.8321 cut off sensitivity 95% BI 2 0.95 (0.94–0.96) 3 0.87 (0.86–0.88) 4 0.81 (0.79–0.82) 5 0.75 (0.73–0.76) 6 0.61 (0.59–0.63) 7 0.47 (0.45–0.49) cut off specificity 95% BI 2 0.48 (0.47–0.49) 3 0.61 (0.60–0.62) 4 0.72 (0.71–0.72) 5 0.74 (0.73–0.75) 6 0.85 (0.84–0.86) 7 0.90 (0.89–0.91) cut off LR+ BI 2 1.60 (1.36–1.88) 3 2.13 (1.79–2.54) 4 2.73 (2.46–3.03) 5 2.86 (2.54–3.24) 6 4.07 (3.36–4.92)	• Risk of bias: very low • Meta analysis of high quality • Risk of publication bias low • A lineair mixed modeling approach reduces the effect of heterogeinity of the study populations

				7 4.85 (3.97–5.94) cut off LR- BI 2 0.12 (0.08–0.19) 3 0.23 (0.18–0.28) 4 0.27 (0.24–0.31) 5 0.33 (0.29–0.36) 6 0.42 (0.37–0.48) 7 0.53 (0.46–0.60)	
• (King et al., 2010)	• Design: meta-analysis • Source of funding: AstraZeneca • Search date: period: 1993-2002 • Searched databases: EMBASE, MEDLINE, PREMEDLINE, CINAHL, Current Contents, PsychINFO, and FACIT Projects Register (administered by CORE) for unpublished information • Included study designs: descriptive/correlative (validation) studies, with cross sectional and/ or longitudinal data collection • Number of included studies:71	• Eligibility criteria: • Exclusion: did not report any FACT-G scores or reported the mean score of only one group at one time, reported FACT-G scores from a total sample of less than 10 patients , or repeated measures from a sample with greater than 20% attrition included if: provided at least one informative contrast, that is, the mean difference between two independent groups (cross sectional contrast) or the mean change within a group over time (longitudinal contrast) • Patient characteristics: age: 58 (27-75), 58% male (0-100%), mixed cancers, all stages, mostly a Western research population	• Index test(s): FACT-G (version 1-4, or not reported) Reference standard: three ‘‘experts’’, predicted the relative magnitude of HRQOL mean differences. Size classes (small, medium, large) were defined in terms of relevance to clinical decision making	Expert judgments were linked with FACT-G results and inverse variance-weighted mean effect sizes calculated for each size class. Effect size classes (small, medium, large) were defined in terms of relevance to clinical decision making. a clinically relevant difference was one that implied a difference in their prognosis and/or clinical management. Evidence-based experts defined estimates for each domain against Cohen’s guidelines categories: <u>Cross sectional estimates (small, medium and larges Effect sizes)</u> • physical well-being 0.42, 0.87, 1.6; • functional well-being 0.37, 0.71, 1.6; • emotional well-being 0.32, 0.40, no large differences • social well-being 0.14, 0.23, no large differences <u>Longitudinal estimates (small and medium effect sizes):</u> • physical well-being 0.26, 0.34; • functional well-being 0.14, 0.28; • emotional well-being 0.27, 0.23; • social well-being 0.08, 0.01 There was virtually no evidence for large longitudinal effects. These results provide specific, evidence-based alternatives to Cohen’s generic guidelines, for use in sample-size calculations for the FACT-G and interpretation of the clinical significance of effects measured with FACT-G.	• Risk of bias: high • No information is given about the quality of the original studies, nor about the risk of publication bias. • Statistic analysis of the pooled accuracy measures seem appropriate
• (Luckett et al., 2011)	• Design: review • Source of funding: Cancer Institute New	• Eligibility criteria: English language, focused exclusively on	• Index test(s): FACT-G and EORTC QLQ30	Psychometric evidence does not recommend one questionnaire over the other in general. However, there are important differences between the scale	• Risk of bias: high • No information is given about the quality of the

<table>
<tr>
<td></td>
<td>South Wales, Australia
• Search date: May 2009 (period: 1993-2009)
• Searched databases: Medline, PsychINFO
• Included study designs: descriptive/correlative (validation) studies
• Number of included studies: 14</td>
<td>reports that mentioned reliability, validity, responsiveness or information useful in interpreting scores of the QLQ-C30 or FACT-G
• Patient characteristics: mixed cancers, all stages</td>
<td>• Reference standard: standardized checklist</td>
<td>structure, social domains and tone that inform choice for any particular study.
<table>
<tr><th></th><th colspan="2">Evidence available
Strongly supportive</th><th colspan="2">Limited or mixed</th><th colspan="2">Unfavourable</th></tr>
<tr><th></th><th>QLQ-C30</th><th>FACT-G</th><th>QLQ-C30</th><th>FACT-G</th><th>QLQ-C30</th><th>FACT-G</th></tr>
<tr><td>IC</td><td>1 (3%)</td><td>13 (41%)</td><td>27 (90%)</td><td>15 (47%)</td><td>2 (7%)</td><td>4 (12%)</td></tr>
<tr><td>TR</td><td>1 (33%)</td><td>9 (75%)</td><td>2 (67%)</td><td>3 (25%)</td><td></td><td></td></tr>
<tr><td>IR</td><td></td><td></td><td>4 (80%)</td><td></td><td>1 (20%)</td><td></td></tr>
<tr><td>CV</td><td></td><td>1 (33%)</td><td>1 (100%)</td><td>2 (67%)</td><td></td><td></td></tr>
<tr><td>IS</td><td>9 (43%)</td><td></td><td>11 (52%)</td><td>8 (100%)</td><td>1 (5%)</td><td></td></tr>
<tr><td>Con V</td><td>12 (64%)</td><td>16 (73%)</td><td>7 (36%)</td><td>6 (27%)</td><td></td><td></td></tr>
<tr><td>DV</td><td>14 (48%)</td><td>17 (63%)</td><td>15 (52%)</td><td>10 (37%)</td><td></td><td></td></tr>
<tr><td>PV</td><td>1 (33%)</td><td></td><td>2 (67%)</td><td></td><td></td><td></td></tr>
<tr><td>FCE</td><td></td><td></td><td></td><td>1 (100%)</td><td>5 (100%)</td><td></td></tr>
<tr><td>Resp</td><td>4 (20%)</td><td>3 (37%)</td><td>12 (75%)</td><td>5 (63%)</td><td></td><td></td></tr>
</table>
</td>
<td>original studies, nor about the risk of publication bias.</td>
</tr>
<tr>
<td>• (Oldenmenger, de Raaf, de Klerk, & van der Rijt, 2013)</td>
<td>• Design: systematic review
• Source of funding: no funding received
• Search date: period: until July 2011
• Searched databases: Medline, PsychINFO, CINAHL, EMBASE
• Included study designs: prospective and retrospective, with primary or secondary analysis
• Number of included studies: 18</td>
<td>• Eligibility criteria: English language, focused exclusively on reports that performed statistical tests to determine the optimal cut point for the ESAS on a 0-10 NRS
• Patient characteristics: mixed cancers, all stages</td>
<td>• Index test(s): ESAS (pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, well-being, and shortness of breath, measured on an NRS or an equivalent instrument.
• Reference standard: standardized checklist: BPI-I, VRS, FACT-F, HADS, FAACT-A,</td>
<td>Cut points:
Moderate pain: 5
Severe pain: 7
Moderate tiredness: 4
Severe tiredness: 7 or 8

A symptom score ≥ 4 is recommended as a trigger for a more comprehensive symptom assessment.</td>
<td>• Risk of publication bias high
• Heterogeneity of patient populations makes interpretation prone to bias
• No information is given about the quality of the original studies</td>
</tr>
</table>

IC, internal consistency; TR, test-retest reliability; IR, interrater reliability; CV, content validity; IS, internal structure; Con V, convergent or divergent validity; DV, discriminant validity; PV, predictive validity; FCE, floor and ceiling effects; Res, responsiveness. NA, not applicable, NRS = numeric rating scale; BPI = Brief Pain Inventory; BPI-I = BPI interference items; ESAS = Edmonton Symptom Assessment Scale; BFI-I = Brief Fatigue Inventory interference items; FACT-F = Functional Assessment of Cancer; Therapy-Fatigue subscale; BFI = Brief Fatigue Inventory; HADS = Hospital Anxiety and Depression Scale; HADS-D = Hospital Anxiety and Depression Scale-Depression subscale; HADS-A = Hospital Anxiety and Depression Scale-Anxiety subscale; FAACT-A = Functional Assessment of Anorexia/Cachexia Treatment-Anorexia subscale; VRS = verbal rating scale.

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Uitgangsvraag 5.3
Welk afkappunt van de lastmeter, eortc qlq c30 of sipp is het meest geschikt voor het signaleren van distress bij volwassen kankerpatiënten?

Table 1 Systematic review distress thermometer

Study ID	Method	Patient characteristics	Interventions	Results	Critical appraisal of study quality, other comments
Ma 2014 [1]	• SR + MA • Funding/CoI: no funding; none reported • Search date: Sep 2013 • Databases: PubMed, Embase • Study designs: comparative cohort studies • N included studies:42 (14.808 patients)	• Eligibility criteria: patients diagnosed with cancer, DT used to detect psychological disorders, (unspecified) reference standard used, sufficient data to construct a 2x2 table • A priori patient characteristics: ○ Mean age: not given ○ Female: not given ○ Tumour sites: mixed in 29 studies ○ Studies from 20 different countries included ○ 2, 3, 4, 5, 6, 7 were all recommended as optimal cut-off in different studies • Disease prevalence: not given	Index test: DT vs. Reference standard: 10 different reference standards	**DT vs. all reference standards:** See table 2 below Best balance of Se and Sp at a cut-off score of 4 **DT vs. HADS-total:** See Table 2 below Best balance of Se and Sp at a cut-off score of 4 **DT vs. HADS-Anxiety:** See Table 2 below Best balance of Se and Sp at a cut-off score of 4 **DT vs. HADS-Depression:** See Table 2 below Best balance of Se and Sp at a cut-off score of 4 **DT vs. BSI:** See table 2 below Best balance of Se and Sp at a cut-off score of 5 **DT vs. DSM-IV:** See table 2 below Best balance of Se and Sp at a cut-off score of 4 **DT vs. any reference standard by cancer trajectory:** See Table 3 below Active treatment: a cut-off score of 6 best balanced the pooled sensitivity (0.73, 95 %CI: 0.68–0.77) and specificity (0.78, 95%CI: 0.76–0.81; AUC: 0.8498) Survivorship: pooled sensitivity (0.71, 95%CI: 0.67–0.74) and specificity (0.83, 95%CI: 0.81–0.84) balances well at the cutoff score of 4 (AUC: 0.8247) End of life: pooled results from three articles at cut-off scores of 4 and 5 had specificities of both less than 0.60. One study reported a sensitivity of 0.65 and a specificity of 0.72 at the cut-off score of 6	SR of good quality • Cut-off for distress evaluated • QUADAS used to check quality of included studies: 6/42 studies scored 100%; 19 studies scored 93%; 17 studies scored 86% • Only results of reference standards for which 3 or more studies were available reported here

Abbreviations: AUC: area under the curve; BSI-18: Brief Symptom Inventory-18; CI: confidence interval; CoI: conflicts of interest; DT: distress thermometer; DSM-IV: Diagnostic and Statistical Manual of Mental Disorders, fourth edition; MA: meta-analysis; NLR: negative likelihood ratio; PLR: positive likelihood ratio; Se: sensitivity; Sp: specificity; SR: systematic review

Table 2 Pooled estimates of the sensitivity, specificity, PLR, NLR, DOR, AUC, and p value of the DT, by reference standard and cut-off score (Ma 2014 [1])

DT cut-off	N1a	N2b	Pooled Sensitivity		Pooled Specificity		Pooled PLR		Pooled NLR		Pooled DOR		AUC
All													
2	19	8,363	0.95	(0.94–0.96)	0.48	(0.47–0.49)	1.60	(1.36–1.88)	0.12	(0.08–0.19)	14.25	(8.90–22.80)	0.885
3	28	10,677	0.87	(0.86–0.88)	0.61	(0.60–0.62)	2.13	(1.79–2.54)	0.23	(0.18–0.28)	11.00	(8.31–14.55)	0.8297
4	64	17,229	0.81	(0.79–0.82)	0.72	(0.71–0.72)	2.73	(2.46–3.03)	0.27	(0.24–0.31)	11.31	(9.60–13.34)	0.8321
5	44	15,940	0.75	(0.73–0.76)	0.74	(0.73–0.75)	2.86	(2.54–3.24)	0.33	(0.29–0.36)	10.37	(8.69–12.38)	0.83
6	29	9,876	0.61	(0.59–0.63)	0.85	(0.84–0.86)	4.07	(3.36–4.92)	0.42	(0.37–0.48)	11.21	(9.38–13.39)	0.8346
7	26	9,129	0.47	(0.45–0.49)	0.90	(0.89–0.91)	4.85	(3.97–5.94)	0.53	(0.46–0.60)	10.60	(9.19–12.23)	0.8347
HADS-A													
2	2	1,601	0.91	(0.88–0.93)	0.65	(0.62–0.67)	2.05	(1.17–3.59)	0.09	(0.02–0.49)	19.90	(7.15–55.41)	–
3	5	2,191	0.83	(0.80–0.86)	0.72	(0.70–0.74)	2.72	(1.87–3.94)	0.23	(0.13–0.42)	13.91	(8.09–23.91)	0.8494
4	9	3,081	0.79	(0.76–0.81)	0.80	(0.78–0.82)	3.21	(2.36–4.37)	0.24	(0.17–0.34)	14.23	(10.49–19.30)	0.8618
5	4	2,004	0.71	(0.67–0.75)	0.83	(0.81–0.85)	3.25	(1.51–7.00)	0.22	(0.10–0.48)	16.29	(12.43–21.36)	0.8743
6	5	2,124	0.55	(0.51–0.59)	0.90	(0.89–0.92)	5.66	(2.87–11.17)	0.36	(0.22–0.59)	15.09	(10.80–21.09)	0.8825
7	3	1,617	0.36	(0.31–0.41)	0.95	(0.93–0.96)	5.50	(1.90–15.86)	0.43	(0.19–1.00)	12.65	(8.44–18.96)	0.8543
HADS-D													
2	2	1,601	0.92	(0.88–0.95)	0.56	(0.53–0.59)	1.72	(0.80–3.72)	0.15	(0.09–0.23)	13.34	(5.57–31.97)	–
3	4	2,300	0.84	(0.79–0.87)	0.64	(0.61–0.66)	2.03	(1.30–3.17)	0.27	(0.21–0.34)	10.30	(7.59–13.99)	0.8289
4	9	2,899	0.77	(0.73–0.81)	0.75	(0.73–0.76)	2.78	(1.93–4.01)	0.35	(0.26–0.46)	10.51	(8.06–13.70)	0.832
5	5	2,108	0.71	(0.65–0.76)	0.76	(0.74–0.78)	2.59	(1.49–4.50)	0.34	(0.22–0.51)	10.63	(7.88–14.34)	0.8317
6	4	1,965	0.57	(0.50–0.63)	0.83	(0.82–0.85)	2.97	(1.78–4.94)	0.33	(0.15–0.70)	9.01	(6.60–12.29)	0.8344
7	3	1,617	0.45	(0.38–0.51)	0.89	(0.87–0.91)	3.48	(1.70–7.12)	0.32	(0.09–1.11)	10.21	(7.02–14.85)	0.8487
HADS-T													
2	9	3,142	0.98	(0.96–0.99)	0.48	(0.46–0.50)	1.64	(1.39–1.94)	0.07	(0.04–0.12)	23.85	(12.84–44.29)	0.8529
3	12	4,018	0.89	(0.87–0.91)	0.64	(0.63–0.66)	2.26	(1.81–2.81)	0.18	(0.12–0.27)	13.74	(9.09–20.76)	0.8281
4	27	7,023	0.82	(0.80–0.84)	0.73	(0.72–0.74)	2.79	(2.40–3.25)	0.24	(0.19–0.31)	12.68	(9.74–16.51)	0.8432
5	20	7,258	0.75	(0.73–0.77)	0.74	(0.73–0.75)	2.82	(2.40–3.31)	0.33	(0.29–0.38)	9.97	(7.77–12.79)	0.8258
6	10	3,156	0.63	(0.59–0.66)	0.87	(0.85–0.88)	4.54	(3.01–6.84)	0.44	(0.37–0.52)	12.46	(8.62–18.01)	0.8426
7	10	3,124	0.47	(0.43–0.50)	0.92	(0.90–0.93)	5.56	(3.64–8.49)	0.59	(0.53–0.66)	11.35	(8.84–14.58)	0.8458
BSI-18													
2	2	1,133	0.98	(0.96–1.00)	0.34	(0.31–0.37)	1.52	(1.37–1.68)	0.05	(0.02–0.15)	28.58	(9.85–82.98)	–
3	2	1,133	0.96	(0.92–0.98)	0.48	(0.45–0.51)	1.90	(1.65–2.18)	0.09	(0.05–0.18)	19.48	(9.67–39.26)	–
4	4	1,633	0.82	(0.77–0.86)	0.63	(0.60–0.65)	2.57	(2.03–3.26)	0.26	(0.12–0.58)	11.03	(5.25–23.18)	0.822
5	5	2,824	0.77	(0.73–0.80)	0.71	(0.69–0.73)	3.16	(2.41–4.15)	0.29	(0.17–0.50)	11.78	(5.72–24.26)	0.8395
6	2	1,133	0.71	(0.64–0.77)	0.78	(0.75–0.80)	3.52	(2.43–5.10)	0.37	(0.28–0.49)	9.98	(4.74–20.98)	–
7	2	1,133	0.59	(0.52–0.66)	0.85	(0.83–0.87)	4.11	(3.04–5.57)	0.48	(0.41–0.57)	8.33	(5.94–11.67)	–
DSM-IV													
2	1	275	98	%	30	%	–	–	–	–	–		
3	1	275	95	%	40	%	–	–	–	–	–		
4	9	1,594	0.84	(0.80–0.88)	0.63	(0.61–0.66)	2.46	(1.81–3.34)	0.29	(0.19–0.45)	9.52	(4.95–18.29)	0.7927
5	5	942	0.81	(0.74–0.87)	0.67	(0.64–0.71)	2.87	(1.83–4.49)	0.31	(0.22–0.43)	9.18	(4.85–17.39)	0.846
6	4	737	0.66	(0.57–0.75)	0.86	(0.83–0.88)	4.52	(3.50–5.84)	0.41	(0.32–0.53)	11.01	(6.98–17.38)	0.8306
7	4	737	0.55	(0.46–0.64)	0.90	(0.88–0.93)	5.37	(3.92–7.35)	0.51	(0.42–0.61)	10.85	(6.92–17.04)	0.7309

PLR positive likelihood ratio, NLR negative likelihood ratio, DOR diagnostic odds ratio, AUC area under the curve, DT Distress Thermometer, HADS-A Hospital Anxiety and Depression Scale-Anxiety, HADS-D Hospital Anxiety and Depression Scale-Depression, HADS-T Hospital Anxiety and Depression Scale-Total, BSI-18: Brief Symptom Inventory-18; DSM-IV: Diagnostic and Statistical Manual of Mental Disorders, fourth edition
a Number of studies
b Number of patients

Table 3 Pooled estimates of the sensitivity, specificity, PLR, NLR, DOR, AUC, and p value of the DT, by cancer trajectory (Ma 2014 [1])

DT cut-off	N1a	N2b	Pooled Sensitivity		Pooled Specificity		Pooled PLR		Pooled NLR		Pooled DOR		AUC
Active treatment													
2	6	1,550	0.98	(0.96–0.99)	0.20	(0.18–0.23)	1.24	(1.06–1.46)	0.15	(0.04–0.58)	8.20	(1.93–34.84)	0.9947
3	10	2,743	0.88	(0.86–0.91)	0.49	(0.46–0.51)	1.76	(1.29–2.40)	0.24	(0.15–0.39)	8.47	(4.35–16.51)	0.8268
4	21	5,068	0.84	(0.82–0.86)	0.66	(0.64–0.67)	2.40	(2.01–2.87)	0.21	(0.15–0.30)	11.30	(8.13–15.70)	0.8091
5	14	5,614	0.76	(0.74–0.78)	0.68	(0.67–0.70)	2.49	(2.14–2.89)	0.31	(0.26–0.38)	8.42	(6.38–11.11)	0.8053
6	9	1,691	0.73	(0.68–0.77)	0.78	(0.76–0.81)	3.74	(2.85–4.90)	0.33	(0.25–0.45)	12.53	(9.22–17.03)	0.8498
7	9	1,610	0.64	(0.59–0.69)	0.86	(0.84–0.88)	4.89	(3.60–6.63)	0.41	(0.32–0.53)	13.68	(9.96–18.80)	0.8619
Survivorship													
2	5	4,233	0.90	(0.88–0.92)	0.62	(0.60–0.63)	2.03	(1.65–2.50)	0.16	(0.10–0.27)	13.62	(7.42–25.01)	0.8605
3	6	4,337	0.79	(0.76–0.82)	0.74	(0.72–0.75)	2.68	(2.14–3.35)	0.29	(0.22–0.38)	10.48	(7.15–15.35)	0.8281
4	6	4,353	0.71	(0.67–0.74)	0.83	(0.81–0.84)	3.59	(2.73–4.73)	0.37	(0.29–0.46)	10.91	(7.28–16.34)	0.8247
5	8	4,561	0.63	(0.59–0.66)	0.87	(0.86–0.88)	4.69	(3.86–5.70)	0.44	(0.38–0.50)	12.00	(9.25–15.56)	0.8466
6	5	4,233	0.45	(0.41–0.49)	0.92	(0.91–0.93)	5.49	(4.31–7.00)	0.60	(0.55–0.64)	10.13	(8.11–12.65)	0.7608
7	6	4,523	0.37	(0.33–0.40)	0.95	(0.94–0.95)	6.29	(4.82–8.21)	0.62	(0.50–0.75)	10.96	(8.79–13.67)	0.843
End-of-life													
4	3	560	0.88	(0.80–0.94)	0.50	(0.46–0.55)	1.87	(1.62–2.17)	0.12	(0.01–1.27)	14.34	(1.50–136.57)	0.5062
5	3	560	0.83	(0.74–0.90)	0.59	(0.55–0.64)	2.13	(1.86–2.45)	0.30	(0.18–0.51)	6.82	(3.61–12.86)	0.6191
6	1	150	0.65	0.72	–	–	–	–	–				
Mixed													
2	8	2,580	0.98	(0.96–0.99)	0.37	(0.35–0.39)	1.63	(1.48–1.79)	0.07	(0.03–0.15)	23.25	(11.51–46.99)	0.6312
3	12	3,597	0.92	(0.90–0.94)	0.54	(0.52–0.55)	2.17	(1.90–2.47)	0.16	(0.09–0.26)	14.87	(9.60–23.04)	0.814
4	34	7,248	0.81	(0.80–0.83)	0.70	(0.69–0.71)	2.91	(2.59–3.27)	0.28	(0.23–0.34)	11.97	(9.66–14.84)	0.8398
5	19	5,205	0.80	(0.78–0.83)	0.69	(0.68–0.71)	2.77	(2.31–3.33)	0.27	(0.23–0.33)	12.21	(9.90–	0.8438

												15.05)	
6	14	3,802	0.67	(0.64–0.70)	0.80	(0.78–0.81)	4.05	(3.02–5.43)	0.40	(0.35–0.47)	13.29	(9.38–18.83)	0.843
7	11	2,996	0.50	(0.46–0.53)	0.85	(0.83–0.86)	4.06	(2.96–5.57)	0.57	(0.49–0.67)	9.06	(7.04–11.66)	0.8168

Abbreviations: PLR positive likelihood ratio, NLR negative likelihood ratio, DOR diagnostic odds ratio, AUC area under the curve, DT Distress Thermometer
a Number of studies
b Number of patients

EORTC QLQ C30

Table 4 Observational studies EORTC QLQ C30

Study ID	Method	Patient characteristics	Interventions	Results	Critical appraisal of study quality, other comments
Snyder 2010 [2, 3]	• Design: cohort study • Funding/CoI: not reported on • Setting: single centre, United States • Sample size: N=117 • Duration: Jan-May 2006	• Eligibility criteria: diagnosis of breast, prostate, or lung cancer at any stage, aged 18 or older, currently undergoing treatment with chemotherapy, radiation therapy, hormonal therapy, biologic therapy, or therapy as part of a clinical trial • A priori patient characteristics: ○ Mean age 61 years ○ 51% men ○ 77% white ○ 43% breast cancer, 41% prostate cancer, 16% lung cancer ○ Half of the patients had metastatic disease ○ The majority of patients were currently taking hormonal therapies and had previously had surgery ○ Prevalence of supportive care needs: not reported	EORTC QLQ C30 (N=117) vs. SCNS (N=117)	See table 5 below AUCs ≥0.70 were identified for 6 of 14 EORTC domains: physical, emotional, role, global QOL, pain, and fatigue. All 6 domains had sensitivity scores ≥0.85 and specificity scores ≥0.50 The authors did not decide on the most appropriate cut-off: ´The appropriate cut-off depends on the relative importance of false positives and false negatives´	Level of evidence: B (EBRO) • Cut off for supportive care needs evaluated • Scores >2.0 on the SCNS (range: 1-5) represented presence of an unmet need • Patients were recruited for the study using flyers handed out by clinic personnel • Outpatients only • The authors considered it more likely that the EORTC QLQ will be used to identify potential problems for further evaluation (and not used to initiate immediate treatment), and therefore favoured sensitivity over specificity
Snyder 2013 [4, 5]	• Design: cohort study • Funding/CoI: public funding; none • Setting: single centre, Japan • Sample size: N=408 • Duration: not reported on	• Eligibility criteria: breast cancer patients • A priori patient characteristics: ○ Mean age 56 years ○ 100% female ○ median time from diagnosis 701 days (range: 11 to 17,915 days) ○ Prevalence of supportive care needs, mean number of unmet needs per domain: ○ Health system and information: 4.4 ○ Psychological: 4.4 ○ Physical and daily living: 1.4 ○ Patient care and support: 1.3 ○ Sexuality 0.4	EORTC QLQ C30 (N=) vs. SCNS-SF34	See table 6 below AUCs ≥0.70 were found for 6 of 14 EORTC domains: physical, emotional, role, global QOL, pain, and fatigue. All 6 domains had sensitivity ≥0.84 and specificity ≥0.50 The authors did not decide on the most appropriate cut-off: ´The appropriate cut-off depends on the relative importance of false positives and false negatives´	Level of evidence: B (EBRO) • Cut off for supportive care needs evaluated • Scores >2.0 on the SCNS (range: 1-5) represented presence of an unmet need • Outpatients only • Participants were selected at random using a list of visits and a random number table to limit the number of patients enrolled each day

Abbreviations: AUC: area under the curve; CoI: conflicts of interest; SCNS: Supportive Care Needs Survey

Table 5 Cut off scores for the EORTC QLQ C30, with sensitivity and specificity, compared to the SNCS, per subscale

EORTC scale	SCNS item	Cut-off	Sensitivity	Specificity	Positive predictive value	Negative predictive value
Physical function	Work around the home	80	.65	.83	.55	.89
		90	.85	.58	.39	.92
Role function	Work around the home	80	.69	.79	.50	.89
		90	.85	.69	.46	.94
Emotional function	Feelings of sadness	90	.89	.53	.48	.91
		100	.94	.35	.41	.93
Global health/QOL	Feeling unwell a lot of the time	80	.89	.58	.50	.91
		90	.94	.31	.39	.92
Pain	Pain	20	.66	.84	.64	.85
		10	.91	.66	.54	.95
Fatigue	Lack of energy/tiredness	20	.91	.55	.68	.86
		10	.96	.25	.57	.88

Table 6 Cut off scores for the EORTC QLQ C30, with sensitivity and specificity, compared to the SNCS, per subscale [4]

QLQ-C30 Domain	SCNS-SF34 Item	Cutoff	Cohort	Sensitivity	Specificity	Positive Predictive Value	Negative Predictive Value
Physical Function	Work around the home	80	Original [14]	0.65	0.83	0.55	0.89
			Replication	0.40	0.92	0.63	0.82
		90	Original [14]	0.85	0.58	0.39	0.92
			Replication	0.85	0.65	0.45	0.93
Role Function	Work around the home	80	Original [14]	0.69	0.79	0.50	0.89
			Replication	0.69	0.79	0.52	0.88
		90	Original [14]	0.85	0.69	0.46	.94
			Replication	0.85	0.62	0.43	0.93
Emotional Function	Feelings of sadness	90	Original [14]	0.89	0.53	0.48	0.91
			Replication	0.84	0.60	0.58	0.86
		100	Original [14]	0.94	0.35	0.41	0.93
			Replication	0.92	0.42	0.51	0.89
Global Health/QOL	Feeling unwell a lot of the time	70	Original [14]	0.71	0.69	0.52	0.84
			Replication	0.86	0.56	0.33	0.94
		80	Original [14]	0.89	0.58	0.50	0.91
			Replication	0.89	0.45	0.29	0.94
Pain	Pain	20	Original [14]	0.66	0.84	0.64	0.85
			Replication	0.70	0.81	0.62	0.86
		10	Original [14]	0.91	0.66	0.54	0.95
			Replication	0.93	0.54	0.47	0.94
Fatigue	Lack of energy/ tiredness	30	Original [14]	0.77	0.71	0.73	0.75
			Replication	0.86	0.62	0.54	0.90
		20	Original [14]	0.91	0.55	0.68	0.86
			Replication	0.97	0.42	0.46	0.97

[14] refers to Snyder 2010 [2]publication

SIPP

Table 7 Observational studies SIPP

Study ID	Method	Patient characteristics	Interventions	Results	Critical appraisal of study quality, other comments
Braeken 2011 [6]	• Design: cohort study • Funding/CoI: not reported on • Setting: single centre, the Netherlands • Sample size: N=76 • Duration: Jan 2006-Mar 2008	• Eligibility criteria: cancer patients treated with radiotherapy • A priori patient characteristics: ○ Not given for the subset of 76 patients of interest ○ Prevalence of distress: 19.7% clinical or subclinical symptoms of distress	SIPP (N=76) vs. SCID-I (N=76)	See table 8 below	Level of evidence: B (EBRO) • Cut off for distress evaluated • Patient selection was based on the availability of the interviewer and the patient without regard to other characteristics (convenience sample) • The interview identified 9 patients with clinical symptoms of whom 4 had an adjustment disorder and 5 a major depressive disorder. The interview identified 6 patients with subclinical symptoms (i.e. those symptoms that do not fulfil standard diagnostic criteria for the diagnosis of an anxiety or mood disorder) including 3 patients with minor depression, 2 with symptoms of anxiety, and 1 with symptoms of both anxiety and depression

Abbreviations: CoI: conflicts of interest; SCID-I: Structured Clinical Interview for DSM-IV-I; SIPP: Screening Inventory of Psychosocial Problems

Table 8 Sensitivity and specificity of physical and psychological complaints of the SIPP (Braeken 2011 [6])

Cut-off points SIPP for clinical distress symptoms	Sensitivity (%)	Specificity (%)	Cut-off points SIPP for subclinical distress symptoms	Sensitivity (%)	Specificity (%)
Physical complaints					
0/1	100.0	20.3	0/1	100.0	22.4
1/2	100.0	35.9	1/2	100.0	39.7
2/3	100.0	50.0	2/3	100.0	55.2
3/4	100.0	62.5	3/4	84.6	65.5
4/5	100.0	71.9	**4/5**	**76.9**	**74.1**
5/6	**100.0**	**79.7**	5/6	69.2	81.0

6/7	85.7	87.5	6/7	46.2	86.2
7/8	57.1	90.6	7/8	30.8	89.7
8/9	42.9	92.2	8/9	23.1	91.4
9/10	28.6	93.7	9/10	15.4	93.1
10/11	28.6	95.3	10/11	15.4	94.8
11/12	14.3	98.4	11/12	7.7	98.3
Psychological complaints					
0/1	100.0	15.6	0/1	100.0	17.2
1/2	100.0	31.2	1/2	100.0	34.5
2/3	100.0	53.1	2/3	100.0	58.6
3/4	100.0	65.6	3/4	100.0	72.4
4/5	100.0	71.9	4/5	84.6	75.9
5/6	100.0	73.4	**5/6**	**84.6**	**77.6**
6/7	100.0	84.4	6/7	76.9	87.9
7/9	100.0	85.9	7/9	69.2	87.9
9/10	**100.0**	**89.1**	9/10	69.2	91.4
10/11	85.7	92.2	10/11	61.5	94.8
11/12	85.7	96.9	11/12	53.8	98.3
12/13	71.4	96.9	12/13	46.2	98.3
13/15	57.1	98.4	13/15	38.5	100.0
15/18	57.1	100.0	15/18	30.8	100.0
18/20	14.3	100.0	18/20	7.7	100.0

According to different cut-off points in detecting clinical and subclinical symptoms of psychosocial distress
Suggested cut-off scores are in bold
SIPP, Screening Inventory of Psychosocial Problems; SCID, structured clinical interview for DSM I

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Uitgangsvraag 7

Wie bespreekt wat, wanneer en hoe met de patiënt, n.a.v. de uitkomsten van het instrument?

Primaire studies: observationele en kwalitatieve studies

Study ID	Characteristics	Background	Methodology	Results	Other comments
Absolom 2011 [1]	• Design: qualitative study • Funding/CoI: public funding; none reported • Setting: various hospitals, United Kingdom • Sample size: N= 23 professionals (6 clinical nurse specialists, 8 oncologists, 4 surgeons, 5 ward sisters) • Duration: not reported	This study describes how key professionals (oncologists, surgeons, specialist and ward nurses) perceive their roles and responsibilities in relation to patient distress and access to specialist support service ´Six years after publication of the NICE guidance on improving supportive and palliative cancer care in the United Kingdom, this study describes how key professionals (oncologists, surgeons, specialist and ward nurses) perceive their roles and responsibilities in relation to patient distress and access to specialist support services.´ NICE´s guidance fundamental premise was that patients' distress should be regularly assessed and addressed by staff with the appropriate skills and knowledge	• Lists of eligible professionals for each centre were compiled and individuals selected at random • Selected professionals were contacted via email/telephone, sent the study information and invited for interview. All participants provided written consent. Interviews lasted 25–55 min, were audio recorded and transcribed verbatim • A semi-structured interview schedule was used • The interview data were analysed using framework analysis	Quotes: ´ Oncologists and surgeons felt able to deal with the distress related to clinical problems and uncertainties and also saw themselves as a 'facilitator', referring patients on to other professionals. CNSs view the management of patients' ED as one of their key responsibilities but liaise closely with the consultants, GPs and the wider MDT to manage ED and guide decisions around care. The CNSs provide personal patient support, exhibiting flexibility in terms of their approach and contact with individuals, offering home visits and telephone access to aid both with the detection and subsequent management of ED. Oncologists perceived the CNS as a 'crutch' for patients but also appreciate they are a stretched resource. Of the health professionals interviewed the CNS role appears to be the most affected by the responsibility for successfully handling distress.´ ´ Ward nurses were happy to manage low levels of distress through talking to patients and advising on available services but also relied on the CNS to manage distressed patients and described using the CNS as a role model for interacting with patients.´ ´ when it comes to appropriate management of distressed patients, the CNSs are heavily relied upon to further assess patients, to provide emotional support and to refer to specialist services. Oncologists and surgeons gave priority to cancer treatment and generally did not consider the management of ED to be a key part of their role.´	• The professionals seem to work in environments were routine screening has not been implemented

Abbreviations: CNS: clinical nurse specialist; CoI: conflicts of interest; DGH: district general hospital; ED: emotional distress; GP: general practitioner; MDT: multidisciplinary team

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Uitgangsvraag 9

Wat zijn de organisatorische randvoorwaarden waarbinnen signaleren van klachten/detecteren behoefte zorg (signalering, gesprek en verwijzing) succesvol kan worden toegepast?

Systematic reviews

Study ID	Characteristics	Background	Synthesis methodology	Results	Other comments
Luckett 2013 [1]	• Systematic review of qualitative studies • Funding/CoI: public funding; none to report • Search date: 2000-May 2011 • Databases: Medline, PsycINFO, Embase, AMED, CINAHL, and Sociological Abstracts • Study designs: qualitative studies • N included studies: 65 (48 patient, 19 caregiver, and 21 health care provider samples)	• Aim: to develop insights for managing barriers and optimizing facilitators to adult cancer pain assessment and management within a comprehensive framework of patient care	• Thematic synthesis followed a three-stage approach using Evidence for Policy and Practice Information and Co-ordinating Centre-Reviewer 4 software: 1) free line by-line coding of ‘‘Results,’’ 2) organization into ‘‘descriptive’’ themes, and 3) development of ‘‘analytical’’ themes informative to our objective	• Mead and Bower’s model of patient centered care accommodated 85% of the descriptive themes. This model describes five dimensions of patient-centered care (biopsychosocial perspective, ‘‘patient as person,’’ sharing power and responsibility, therapeutic alliance, and ‘‘doctor as person’’) and identifies influential factors relating to the patient, health professional, consultation, professional context, and societal ‘‘shapers’’ ○ Within the context of consultation, formal tools for assessing pain were perceived to be helpful in the doctor-patient communication by some patients, but not by all • 12% more related to the caregiver and service/system factors ○ The health professionals were sometimes skeptical of the usefulness of formal pain assessment tools, preferring to use clinical judgment involving ‘‘objective’’ as well as ‘‘subjective’’ indicators ○ The health professionals reported somewhat negative perceptions of guidelines, including those for cancer pain. In a South African study, HP knowledge of standards was reported to be variable ○ The health professionals sometimes admitted that they lacked knowledge, especially with regard to breakthrough pain and unfamiliar treatments such as intrathecal infusions. Medical and nursing students and faculty interviewed in one study pointed to scant coverage of pain in general and cancer pain in particular ○ The health professionals acknowledged the usefulness of pain charts and audits in helping them reflect on practice to improve future management • Three themes could not be accommodated, including: need for frequent assessment	EBRO: C (non-comparative study) • Slightly other focus than research question • The authors undertook a quality appraisal though no general consensus exists on what quality items to score for qualitative studies (Kitto et al. checklist was used) • Less than 50% of studies met the following quality criteria: ○ Clarification of research question: 14% ○ Justification for qualitative research: 49% ○ Justification for specific design: 34% ○ Sampling techniques described: 49% ○ The interpretation had a linkage to the theory: 32% ○ Negative cases were reported: 6% ○ Researcher´s views and methods were reported: 26% ○ Researcher-participant relation was clarified: 20% • Thus, out of the 15 quality items scored, 8 quality items were not met by half of the studies

Primaire studies: observationele en kwalitatieve studies

Study ID	Characteristics	Background	Methodology	Results	Other comments
Absolom 2011 [2]	• Design: qualitative study • Funding/CoI: public funding; none reported • Setting: various hospitals, United Kingdom • Sample size: N= 23 professionals (6 clinical nurse specialists, 8 oncologists, 4 surgeons, 5 ward sisters) • Duration: not reported	This study describes how key professionals (oncologists, surgeons, specialist and ward nurses) perceive their roles and responsibilities in relation to patient distress and access to specialist support service ´Six years after publication of the NICE guidance on improving supportive and palliative cancer care in the United Kingdom, this study describes how key professionals (oncologists, surgeons, specialist and ward nurses) perceive their roles and responsibilities in relation to patient distress and access to specialist support services.´ NICE´s guidance fundamental premise was that patients' distress should be regularly assessed and addressed by staff with the appropriate skills and knowledge	• Lists of eligible professionals for each centre were compiled and individuals selected at random • Selected professionals were contacted via email/telephone, sent the study information and invited for interview. All participants provided written consent. Interviews lasted 25–55 min, were audiorecorded and transcribed verbatim • A semi-structured interview schedule was used • The interview data were analysed using framework analysis	<u>Barriers/limitations to successful implementation:</u> • Roles and responsibilities • Use of screening tools (advantages and disadvantages) • Practical issues (time, environment) • Lack of referral guidance • Access to specialist psychological/psychiatric care and other supportive services • Skills and training needs <u>Quotes</u>: ´All staff accepted responsibility for the detection of ED and viewed the multi-disciplinary team approach to be essential, although it was acknowledged that this could dilute individual responsibility´ ´[..] while accepting responsibility and recognising that ED may be under-diagnosed, generally oncologists and surgeons do not see detection as part of their day-to-day role and do not routinely explore unless it influences treatment plans or if the patient explicitly discloses problems. […]The reluctance of oncologists and surgeons to probe for ED appeared to originate from concerns that focusing on this aspect of care may adversely impact the medical management of cancer and be time consuming´ ´The professionals had limited experience of screening tools but could see their potential advantage in detecting distress that might otherwise go unidentified´ ´Systematic screening was also recognised to have the potential for attracting additional resources if they produced evidence that further psychological support was needed for services´ ´[…] uncertainty about the benefits of screening tools and the desire for evidence of their validity and efficacy in clinical practice were expressed by other professionals´ ´Other perceived disadvantages of screening included the potential barriers of patient literacy levels and the logistics of implementation. Consultants also voiced concerns that the process	EBRO: C (non-comparative study) • The professionals seem to work in environments were routine screening has not been implemented

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				could result in additional demands for services that could not be met´ ´Apprehension about the challenges of integrating screening into everyday practice alongside clinical priorities were also expressed, particularly the additional time needed´ ´Concerns that screening tool completion would unearth distress and be detrimental to the patient were common´ ´All the professional groups viewed time pressures to be a fundamental problem impeding the management of distressed patients.´ ´….the pressures of handling both clinical and emotional care are challenging for all professionals´ ´[…] the clinical setting was not always conducive for managing distress […] commented that the limited privacy on wards and outpatients departments impacted on how comfortable patients felt discussing psychological issues´ ´[…] changes to national policies regarding the organisation of follow-up care now meant that the focus had been taken away from providing extended surveillance of patients following treatment. As a result it was not known how long-term survivors were coping psychologically and how any distress issues were being managed by this group´ ´One of the main issues staff perceived as a barrier to the successful management of ED was poor access to specialist psychological and supportive services. There was considerable disparity in access to clinical psychology across the different hospital locations. Some staff from the DGHs perceived the local cancer centre to be better resourced and equipped. Others were unclear whether there were psychologists in post and/or how to make referrals. Psychology services were perceived to be finite, over burdened and unable to provide timely intervention with patients needing support. As a consequence professionals were reluctant to make referrals as a result of their	

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				past experiences.´ ´For less severe cases, a general absence of clear guidance and a management strategy defining which patients to refer and the procedures involved results in variation in referrals patterns among different oncology teams.´ ´A perception of not having the skills necessary to detect and manage ED was common among the professionals interviewed.´ ´[…] many felt additional ED-specific training would be beneficial. The CNSs were particularly interested in opportunities to receive updates and feedback on their skills in handling distress.´ ´The ward-based nursing staff were also enthusiastic about further training that specifically focussed on ED and helping staff cope with patient distress once it had been disclosed. The ward sisters felt they would, however, have considerable trouble releasing staff for further training due to being under-staffed and not having the finances to support attendance. The oncologists were open to the idea of training in ED but felt compromised with regards to taking time from busy schedules when medical care was their main priority.´	
Clark 2009 [3]	• Design: observational study • Funding/CoI: public funding; not reported on • Setting: single outpatient centre, United States • Sample size: N=not reported how many staff were involved • Duration: Jan-Jun 2007	• Describes a single centre´s experience in implementing touch-screen problem-related distress screening as the standard of care for all outpatients in a health-care setting	• Unclear how the barriers/limitations were examined, and if they were examined systematically e.g. ´ It was the policy of the project team to investigate all complaints and to address them immediately´	<u>Barriers/limitations to successful implementation:</u> • Attitude of the front desk staff: o Fear of added work o Psychosocial team as outsiders o Fear of change o Lack of communication skills to describe instrument and processes o Concerns about disrupting clinic o Do not see importance of screening o Do not understand screening o Manifested latent resistance of health-care professionals o Reject additional demands as a result of pre-existing stress of clinic • Age-related perceptions (illegible, difficult to understand by the elderly) • Language • Health team o Time consuming o Emotional content o Setup costs	EBRO: C (non-comparative study) • None

Study ID	Characteristics	Background	Methodology	Results	Other comments
Dessai 2014 [4]	• Design: observational study • Funding/CoI: not reported on • Setting: outpatient department tertiary care cancer clinic rural India • Sample size: N=not applicable • Duration: single day	• Describes a single centres experience with the implementation of the distress thermometer for one single day	• Not reported on	<u>Barriers/limitations to successful implementation:</u> • Lack of staff: time consumption of screening; 15% of patients could not be screened	EBRO: C (non-comparative study) • Other barriers/limitations except % of outpatients screened were not examined
Dinkel 2010 [5]	• Design: observational study • Funding/CoI: • Setting: 2 university clinics, Germany • Sample size: N=42 (27 nurses/radiographers, 15 physicians) • Duration: not reported	• Objective of the study was to compare computerised and paper-and-pencil screening in terms of acceptability and utility	• Nurses/radiographers and physicians anonymously answered 12 items on a five-point scale from 'completely untrue' to 'completely true'. Items referred to the implementation of the screening procedure, the usability of the two assessment modalities and satisfaction with the assessment	<u>Barriers/limitations to successful implementation:</u> • Of the nurses/radiographers, 18.0% evaluated the paper version as time consuming, as opposed to 3.0% for the computer version. In reality both cost similar staff time namely 6 minutes on average	EBRO: C (non-comparative study) • None
Dudgeon 2012 [6]	• Design: qualitative study • Funding/CoI: not reported on; not reported on • Setting: Multicenter, Canada • Sample size: N=44 • Duration: 2006-2010	• Cancer Care Ontario launched a quality improvement initiative to implement routine screening with the Edmonton Symptom Assessment System (ESAS) for cancer patients seen in fourteen Regional Cancer Centres throughout the province • A multidisciplinary, team-based model was used to develop and test process changes and to facilitate uptake of screening and best practices for assessment and management of symptoms	• Interviews and focus groups were conducted with project participants to determine the successes and challenges • A total of 44 individuals in 14 interviews and 7 focus groups participated in the qualitative component of the evaluation. They included directors and administrators, physicians, managers, regional improvement and steering committee members	<u>Barriers/limitations to successful implementation:</u> • Process: ○ Lack of consensus on the chosen screening tool ○ Lack of guidance for assessment or management of high scores ○ Implementing the initiative across the whole province simultaneously and in both ambulatory and home care populations ○ Electronic platform for data collection was not in place when the project started ○ Centralized data collection created delays in reporting back to regions • Resources: ○ Concern of inadequate time or resources to address issues identified by the screening ○ Labour intensive data entry • People/culture: ○ Resistance to change and challenges to the traditional care model <u>Facilitators for implementation:</u>	EBRO: C (non-comparative study) • Unclear how participants for interviews and focus groups were selected

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				• Centralized project management • A person dedicated to implementation of the project locally • Clinical champions • Clearly identified aims • Monthly regional data reporting • Volunteer involvement • Implementation of quality improvement methodologies with expectations for performance	
Lee 2010 [7]	• Design: observational study • Funding/CoI: public funding; none • Setting: single centre inpatients, Australia • Sample size: N=19 (16 nurses and 3 allied health staff) • Duration: Jun- Aug 2006	• Routine screening with the distress thermometer and BSI-18 was implemented on an inpatient oncology and haematology ward, along with referral pathways	• Staff feedback was requested through a brief anonymous questionnaire	<u>Barriers/limitations to successful implementation:</u> • ´Some concern was expressed about ensuring adequate psychosocial staff to support a potentially increased need´ • Nurses wanted a greater role in conducting the distress screening as the tools prompted patients to discuss issues that otherwise were often not raised	EBRO: C (non-comparative study) • 45% of staff provided feedback
Livingston 2010 [8]	• Design: observational study • Funding/CoI: public funding; none reported • Setting: 6 centres, Australia • Sample size: N=9 (1 nurse, 8 social workers) • Duration: Jun 2008-Sep 2009	• Study´s aim was to test the feasibility and acceptability of distress screening among colorectal cancer patients who had completed training	• Unclear how staff feedback was requested or processed	<u>Barriers/limitations to successful implementation:</u> • Appropriate resources to sustain the programme	EBRO: C (non-comparative study) • None
Mitchell 2008 [9]	• Design: observational study • Funding/CoI: public funding; none to report • Setting: cancer professionals, United Kingdom • Sample size: N=300 (226 responders) • Duration: not reported	• Study´s aim was to assess clinicians' attitudes and practices in relation to screening for distress	• A new questionnaire of clinicians' attitudes and practices in relation to screening for distress was developed and distributed to 300 health professionals working with cancer patients (170 clinical nurse specialists, 50 doctors, remainder were from miscellaneous	<u>Barriers/limitations to successful implementation:</u> • Perceived primary barriers: ○ Time (57.8%) ○ Lack of training on screening methods (16.9%) ○ Low personal skills or confidence about diagnosis (13.3%) ○ Lack of interest (4%) ○ Patients dislike screening (3.1%) ○ Cultural barriers (3.1%) ○ Lack of resources (0.9%) ○ Lack privacy/environment (0.9%) ´77% of non-specialists (group 3) cited either low skills or training as barriers compared to 62% of cancer specialists´ (this refers to low skills mentioned as either a primary or a secondary barrier)	EBRO: C (non-comparative study) • Unclear how representative the sample was: ´Questionnaires were given out in two independent centres (Leicestershire, Northamptonshire, and Rutland Cancer Network and the Greater Manchester & Cheshire Cancer Network). Questionnaires were also distributed at several National Cancer meetings during 2006 including the 8th Annual Conference National Lung

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			groups including speech therapy, occupational therapy and dieticians)		Cancer Forum For Nurses Brighton which attracted clinicians from across the UK.´ • Response: 75.3% • Only perceived primary barriers reported on, though secondary barriers were elicited
Mitchell 2012 [10]	• Design: observational study • Funding/CoI: none, none to report • Setting: single centre, United Kingdom • Sample size: N=50 (20 chemotherapy nurses, 30 radiographers) • Duration: Apr 2009- Mar 2011	• Screening programme with the distress thermometer and/or emotion thermometers were implemented and professionals were surveyed on their experience. All clinicians were invited to use the screener as part of routine care. Clinicians themselves used the screen on each clinical contact without automated help and without assistance from administrative staff. Clinicians were asked to screen all consecutive patients unless there was a clinical reason to avoid screening	• Survey amongst clinicians on their satisfaction with screening, each time a screening was performed (i.e. not with the implementation of the screening programme in general, but on each individual training)	Barriers/limitations to successful implementation: • Professionals believed screening was not useful in 36% of assessments vs. useful in 43% of assessments and neutral in 21% • In 51% of assessments professionals believed that screening helped improve clinical communication • Clinicians believed that the simple paper-and-pencil screening program was impractical for routine use in 37.5% of assessments	EBRO: C (non-comparative study) • A question on whether screening took too long was included in the survey but not reported on as an outcome
Riblet 2014 [11]	• Design: observational study • Funding/CoI: not reported on; none to report • Setting: single centre, United States • Sample size: N=not reported • Duration: Nov 2010-Apr 2012	• The aim was to improve mental health care for patients with head and neck cancers through the implementation of an evidence-based process for identifying and managing psychological distress • The specific goal was to ensure that 100% of patients were screened for distress and, if indicated, received evidence-based treatment • Distress was assessed by the distress thermometer • A quality improvement project was undertaken to improve distress screening rates after implementation	• Not described how barriers/limitations were elicited, except that some meetings were described	Barriers/limitations to successful implementation: • Process/work flow issues: lack of print-outs, change in personnel, treatment algorithm was not user-friendly, time pressure, change in work flow • Heavy reliance on one person (licensed nursing assistant) • Involvement of senior leadership was mentioned as a facilitator	EBRO: C (non-comparative study) • None
Tavernier 2013 [12]	• Design: observational study • Funding/CoI: private funding • Setting: national, United States	• Aim: to explore system and clinician-related barriers, and predictors for the adoption of the National Comprehensive Cancer Network Distress Management Guideline into	• Survey by e-mail/electronically of a national , randomly selected sample of oncology nurses working in	Barriers/limitations to successful implementation: Eight questions using a six-point scale (1=not at all, 6=very much a barrier) made up the Barrier scale, assessing the degree to which identified issues were barriers to screening for distress in the respondents' practice setting. Mean scores were:	EBRO: C (non-comparative study) • Study respondents (n = 409) were predominantly certified nurses (84%) and

Study ID	Characteristics	Background	Methodology	Results	Other comments
	• Sample size: N=409 • Duration: not reported	oncology outpatient practice	an outpatient setting	• Lack of time: 4.1 • Staff uncertainty about how to identify distress: 3.4 • Staff uncertain about treatment options for distress: 3.4 • Lack of clarity about who is responsible for screening: 3.4 • Limited referral resources: 3.2 • Patients unwilling/reluctant to discuss distress 3.2 • Staff uncomfortable discussing distress with patients: 2.9 • Belief that interventions are ineffective: 2.1	largely unfamiliar with the guideline • Low response (23%)
Williams 2009 [13]	• Design: qualitative study • Funding/CoI: public funding; none to report • Setting: single centre, Australia • Sample size: N=19 (staff members who had a role in the screening, assessment and treatment of patients • Duration: not reported	• Aim: to develop a model that improved the way psychosocial services were provided to patients, i.e. to develop a standardised way of screening for psychosocial distress and referring patients to the most appropriate clinician(s) and supports	• Semi-structured interview which focussed on (a) the method for screening and referring patients, (b) the role of different staff in providing psychosocial care, and (c) issues, barriers or concerns with the provision of psychosocial care • Data were analysed qualitatively using inductive thematic analysis	<u>Barriers/limitations to successful implementation:</u> • Various detailed issues with the screening instrument (e.g. missing questions) • Absence of criteria for referral	EBRO: C (non-comparative study) • Unclear how the interviewees were selected and how representative this sample was • Though the methods used was a semi-structured interview focussing on several aspects, issues with the screening instrument were the main outcome of this study

Abbreviations: CNS: clinical nurse specialist; CoI: conflicts of interest; DGH: district general hospital; EBRO: evidence based richtlijn ontwikkeling; ED: emotional distress; SD: standard deviation

Note: EBRO is not well suited to assess the quality of qualitative studies. Some studies had a random sample of professionals that were questioned, whereas in other studies the sampling and questioning methods were not described. All studies were assessed as level C (non-comparative study)

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