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IMPLEMENTING A SCREENING PROGRAMME FOR DISTRESS IN **CANCER SETTINGS: SCIENCE AND PRACTICE**

IMPLEMENTING A SCREENING PROGRAMME FOR DISTRESS IN CANCER SETTINGS: SCIENCE AND PRACTICE

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Abstract

Objective. Previous work has addressed the development and diagnostic validity testing of tools for measuring cancer-related distress. Relatively little has been published on the implementation of these tools in clinical practice. We aimed to review the findings of randomized and non-randomized trials of the effect of distress screening to identify the effectiveness and acceptability of screening programmes.

Methods. A search was made of the Embase/ Medline and Web of knowledge abstract databases from inception to May 2012. Our inclusion criterion was randomized and nonrandomized controlled trials concerning the effect of screening for psychological distress on patient and clinician reported outcomes. We included studies on quality of life.

Results. We identified 21 qualifying studies. Twelve were randomized trials and nine were non-randomized trials of the effect of screening for psychological distress. Six randomized trials assigned patients to receive screening or no screening, the remainder randomized patients to receive feedback or no feedback of screening results. Only 6 of the randomized reported benefits (five as a direct result of screening), although an additional 8 non-randomized studies showed partial benefits. Most benefits were seen in domains

Resumen

Objetivo. El trabajo previo ha abordado el desarrollo y probado la validez diagnóstica de herramientas para medir el malestar emocional asociado al cáncer. Se ha publicado relativamente poco acerca de implementación de estas herramientas en la práctica clínica. Nos propusimos revisar los resultados de los ensavos aleatorios y no aleatorios del efecto del cribado del malestar, para identificar la efectividad y aceptabilidad de los programas de cribado.

Métodos. Se realizó una búsqueda de los abstracts de las bases de datos EMBASE / Medline v Web of Knowledge desde el principio hasta mayo de 2012. Nuestro criterio de inclusión fueron ensavos controlados aleatorios y no aleatorios concernientes al efecto del cribado de malestr psicológico en los resultados informados por pacientes y médicos. Se incluyeron estudios sobre la calidad de vida.

Resultados. Se identificaron 21 estudios cualificados. Los ensavos acerca del efecto del cribado del malestar psicológico fueron 12 aleatorios y 9 nueve no aleatorios. Seis ensayos aleatorizados asignaron a los pacientes para recibir cribado o no cribado, el resto aleatorizó a pacientes para recibir feedback o no feedback de los resultados del cribaje. Sólo 6 de los ensayos aleatorizados informaron beneficios (5 como resultado directo cribado), aunque otros 8 estudios no aleatorios mos-

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of communication, clinician behaviour and patient referral. Acceptability of screening was high during funded screening implementation studies but mixed when incorporated into routine clinical care.

Conclusions. Screening for distress has the potential to influence communication, clinician behaviour and patient referral and to a lesser extent recognition of distress and unmet needs. Barriers to implementation success include low staff confidence, lack of training and support, low acceptability and failure to tie treatment to the screening results. Further work needs to be conducted on the value of screening when incorporated into routine clinical care and into the most appropriate methods for studying the implementation of screening in clinical practice.

Key words: Distress, depression, cancer, oncology, psychosocial, screening, distress thermometer.

traron beneficios parciales. La mayoría de los beneficios se observaron en los dominios de la comunicación, el comportamiento clínico y la derivación de los pacientes. La aceptabilidad del cribado fue alta durante los estudios de implementación del screening financiados pero mezclados cuando se incorporaron a la atención clínica habitual.

Conclusiones. La detección del malestar tiene el potencial de influir en la comunicación, el comportamiento clínico y la derivación de los pacientes y, en menor medida, en el reconocimiento del malestar y de necesidades no satisfechas. Las barreras para su implementación exitosa incluyen baja confianza del personal, la falta de formación y apoyo, baja aceptabilidad y fracaso para asociar el tratamiento a los resultados del cribado. Se necesita trabajar acerca de la valía del cribado cuando se incorpora a la atención clínica habitual, y de los métodos más apropiados para estudiar la implementación del cribado en la práctica clínica.

Palabras clave: Malestar, depresión, cáncer, oncología, psicosocial, cribado, termómetro del malestar.

INTRODUCTION

The Importance of Distress

Distress is the experience of significant emotional upset arising from various physical and psychiatric conditions⁽¹⁻²⁾. Distress can be considered a generic category of emotional suffering that encompasses psychiatric conditions such as depression, anxiety, adjustment disorder in addition to non-psychiatric psychological and practical concerns⁽³⁾. Distress is not a specific category in DSMIV (Diagnostic and Statistical Manual of Mental Disorders, 4th Edition) or ICD10 (International Classification of Diseases, 10th Edition) but appears as a qualifier, along with impaired function, known as the clinical significance criteria. These criteria separate

non-clinical symptoms from clinical mental disorders. Accumulating evidence suggests that the presence of distress is associated with reduced health-related quality of life⁽⁴⁾, poor satisfaction with medical care⁽⁵⁾ and possibly reduced survival after cancer⁽⁶⁾. It is not yet clear, however, to what extent distress adversely influences outcomes once psychiatric disorders are accounted for.

Many frontline cancer clinicians help patients identify and manage distress but overall much distress continues to be overlooked and thus frequently goes untreated. Distress is closely linked with unmet needs and it is well documented that many cancer patients report that their psychosocial and physical needs are not met⁽⁷⁾. Yet distress is a treatable condition; treatment should begin with the attempt to identify and address meetable unmet needs⁽⁸⁾. Accurate and prompt identification of distress, related disorders and unmet needs is probably the most important barrier to successful psychosocial care. Most physicians working with cancer patients are not confident in dealing with distress. Many do not use any screening instrument to identify those with mood disorders or distress⁽⁹⁾ even though reliable and valid tools are available⁽¹⁰⁾.

In recent years several organizations have promoted distress, rather than depression, as the key emotional patientreported outcome measure in cancer care, endorsing it as the "6th Vital Sign" in cancer care⁽¹¹⁾. The distress concept has the advantage of lower perceived stigma than depression, and broad acceptability to patients. Its disadvantage is that distress is poorly operationalized, and overtreatment risks medicalizing patients who have short-lived mild emotional responses to cancer⁽¹²⁾. Nevertheless, as distress is the guintessential self-reported emotional complication, measurement of distress using self-report measures may have more face validity than the equivalent measurement of depression. Screening has been suggested to improve patient outcomes in depression, but positive benefits have equally been disputed^(13,14). Detractors of screening raise two worthwhile cautions. First that screening should apply only to those not already currently recognized as depressed in receipt of treatment; and second that those who screen positive often don't accept the treatment that is offered⁽¹⁵⁾. The same caveats apply to distress with the additional caution that treatment of distress is less evidence-based than the treatment of depression. Thus both routine screening for depression and routine screening for distress are equally controversial and require further study. This may apply not only to general oncology, haematology and surgical settings but also to palliative care.

Details of how to screen and how often to screen are subject to much local variation. According to the National Comprehensive Cancer Network (NCCN), distress should be recognized and monitored through regular and repeated screening and treated promptly at all stages of disease⁽¹⁶⁾. A 2002 US National Institutes of Health (NIH) Conference Statement called for the routine use of screening tools to identify untreated depression among cancer patients⁽¹⁷⁾. The 2004 guidelines from the UK National Institute for Clinical Excellence (NICE)(18) recommended screening for psychological "distress," including depression, in cancer patients. The Cancer Journey Action Group (CJAG) of the Canadian Partnership Against Cancer (CPAC) recommend that patients be screened routinely at critical time points during the cancer continuum⁽¹⁹⁾. A 2007 report from the Institute of Medicine (IOM)⁽²⁰⁾ recommended screening for psychological distress in cancer settings. However, at the time of these recommendations none were able offer a thorough evidence based overview of implementation studies. The aim of screening is fundamentally to facilitate effective and efficient treatment by focussing on people who would most benefit from a proven intervention. Thus tools need to be incorporated into screening programmes which are in turn acceptable to practicing clinicians and patients and, importantly, tied to proven evidence-based treatments. These studies will be reviewed here.

Evaluation of Screening from Design to Implementation

Screening implementation is the process whereby a screening method is developed, applied and tested. Stages of tool development are shown in table 1⁽²¹⁾. First, a suitable tool must be developed. Tools can take a broad approach, for example focussing on distress or quality of life, or a narrow one, focussing on depression or anxiety. Tools may also measure other valuable domains such as unmet needs, desire for help, impaired function, coping styles and therapeutic alliance (trust). Phase I in evaluating a tool is to test its diagnostic validity against an accepted standard in a selected sample in order to provisionally determine its sensitivity and specificity. In Phase II, the diagnostic validity study should be repeated in independent clinically representative samples. If this is successful, a randomized controlled trial (RCT) should be performed, in which outcomes are measured in two similar groups with and without the tool. A Phase III screening trial is the first real test of implementation success. Here a screening tool is evaluated in one group with access to the new assessment method and compared with a second group without access to the tool (or in some cases without access to feedback of the tool results). Ideally a screening trial should be conducted under double-blind

Stage	Туре	Purpose	Description
Pre-clinical	Development	Development of the proposed tool or test	Here the aim is to develop a screening method that is likely to help in the detection of the underlying disorder, either in a specific setting or in all settings. Issues of acceptability of the tool to both patients and staff must be considered in order for implementation to be successful.
Phase I-screen	Diagnostic validity	Early diagnostic validity testing in a selected sample and refinement of tool	The aim is to evaluate the early design of the screening method against a known (ideally accurate) standard known as the criterion reference. In early testing the tool may be refined, selecting most useful aspects and deleting redundant aspects in order to make the tool as efficient (brief) as possible whilst retaining its value.
Phase II-screen	Diagnostic validity	Diagnostic validity in a representative sample	The aim is to assess the refined tool against a criterion (gold standard) in a real world sample where the comparator subjects may comprise several competing conditions which may otherwise cause difficulty regarding differential diagnosis.
Phase III-screen	Implementation trials	Screening trials (randomized and non- randomized); clinicians using vs not using a screening tool	This is an important step in which the tool is evaluated clinically in one group with access to the new method compared to a second group (ideally selected in a randomized fashion) who make assessments without the tool.
Phase IV-screen	Implementation monitoring	Screening implementation studies using real-world outcomes	In this last step the screening tool/method is introduced clinically but monitored to discover the effect on important patient outcomes such as new identifications, new cases treated and new cases entering remission.

Table 1. Stages in the evaluation of the screening test (A	dapted from Mitchell ⁽²¹⁾)
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randomized conditions but other designs such asas before and after studies using historical data may still be valuable. In the last step (Phase IV), the promising screening tool should be introduced into clinical practice under close scrutiny, in order to discover the effect on important patient outcomes such as new cases identified and treated and improvements in other patientreported outcome measures (PROs).

Other authors have reviewed Phase I and II diagnostic validity studies in depth^(10,22-24). In this article we aim to review the evidence from Phase III RCTs of screening for distress in cancer. We included screening of quality of life (QoL) as these overlap with screening for distress.

METHODS

A search was made of the Embase/ Medline and Web of Knowledge abstract databases from inception to May 2012. Our inclusion criterion was randomized controlled trials of the effect of screening for psychological distress on psychological outcomes (including quality of life). We also searched previous reviews^(2,25-27). We examined the following areas: Design and methods, setting and sample, screening and intervention, effect on psychological distress, staff utilization of screening and methodological limitations.

RESULTS

From a total of 495 studies retrieved from a total of three searches, we identified twelve randomized trials of the effect of screening for psychological distress⁽²⁸⁻³⁹⁾. A further nine non-randomized studies measured changes in distress or related outcomes before and after screening without randomization⁽⁴⁰⁻⁴⁸⁾. Several other studies with psychological PROs were not included as they did not randomize or evaluate the effect screening itself; that is they did not include a screening and a no screening condition but randomized only the treatment that followed screening⁽⁴⁹⁻⁵³⁾.

Randomized Studies

Maunsell et al., conducted the first randomized study of its kind, involving 251 breast patients⁽²⁸⁾. Both groups received basic psychosocial care and follow-up telephone interviews 3 and 12 months later, but the intervention group also received telephone screening using the GHQ20 every 28 days (a total of 12 calls). Patients scoring \geq 5 on the GHQ were referred to a social worker. Results showed that distress decreased over time in both groups with little to differentiate between groups and no additional benefit of screening. This was attributed to the high quality of usual care in already addressing psychosocial needs.

Sarna conducted a trial whereby the results of screening with the Symptom Distress Scale (SDS), Hospital Anxiety and Depression Scale (HADS) and Karnofsky Performance Status (KPS) were fed back or not fed back to clinical nurses according to randomization⁽²⁹⁾. The sample was 48 patients within three months of a diagnosis of advanced lung cancer. Over 6 months of follow up symptom distress in the feedback group declined but in the no feedback group it increased and the difference was statistically significant by 6 months. The symptom distress scale includes psychological and physical symptom ratings, but these were presented together and not separated in feedback reports.

McLachlan et al., collected data on self-reported needs, quality of life and psychosocial symptoms from 450 people with cancer, but randomized feedback of screening results to physicians⁽³⁰⁾. Patients completed self-reported questionnaires via a touch-screen computer and if they met all eligibility criteria, they were then randomly allocated to either the intervention or control group in a 2:1 ratio. For the intervention group, a computer-generated one-page summary of the questionnaire results was made available immediately for consideration during the consultation with the doctor. In the intervention arm a nurse was also present during this consultation and formulated an individualized management plan based on the issues raised in the summary report and pre-specified expert psychosocial guidelines. Six months after randomization there were no significant differences between the two arms in any domain or regarding satisfaction with care. However, for the subgroup of patients who were at least moderately depressed at baseline, there was a significantly greater reduction in depression for the intervention arm. Detmar et al., in the Netherlands investigated the effect of assessment of quality of life on staff-patient discussions in a randomized cross-over trial. Patients were randomized to a control group with usual care or to an intervention group in which they were screened with the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30) and the result was made available to the staff⁽³¹⁾. Halfway through physicians switched arms, reducing likelihood of confounding by having different staff in each condition. Results suggested that HRQoL issues were discussed significantly more frequently in the intervention than in the control condition but there was little effect on patient management and patient reported QoL. Sub-group analysis showed there was improvement in HRQoL domains namely, better identification in mental health and role functioning over time. Velikova et al., in Leeds recruited 28 oncologists treating 286 cancer patients and randomly assigned them to an intervention group who underwent screening along with feedback of results to physicians, a screen-only group (attentioncontrol) who completed questionnaires without feedback and a control group with no screening condition^(32,54). The questionnaires used were the EORTC QLQ-C30 and touch-screen version of HADS. A positive effect on emotional well-being was seen in the intervention vs control group but there was little to differentiate intervention and the screeningattention-control. Although more only frequent discussion of chronic non-specific symptoms was found in the intervention group (without prolonging encounters), there was no detectable effect on patient management. Clinician satisfaction was also monitored prospectively. Physicians found the HRQoL information clinically "very useful/quite useful" in 43% of encounters, "somewhat useful" in 28%, "little useful" in 21%, and "not useful" (or missing response) in 9%. They felt that the HRQoL screening data provided additional information in 33% of cases and identified problems for discussion in 27%. By physician report it contributed to patient management in only 11% of encounters.

Rosenbloom et al., randomly assigned 213 patients with metastatic breast, lung or colorectal cancer to feedback or no feedback following screening with the Functional Assessment of Cancer Therapy-General (FACT-G)⁽³³⁾. The main intervention group received structured interview by the treating nurse. The authors looked at 3 and 6 month outcomes in QoL, Mood (profile of mood states, POMS-17) and satisfaction. Halfway through physicians switched arms, reducing the likelihood of confounding which could occur by having different staff in each condition. Results suggested that HRQoL issues were discussed significantly more frequently in the intervention than in the control condition but there was little effect on patient management and patient reported QoL. Sub-group analysis showed there was improvement in HRQoL domains namely, in mental health and role functioning over time.

Mills et al., conducted a randomized controlled trial involving 115 patients with inoperable lung cancer⁽³⁴⁾. Participants were randomly assigned to receive either standard care or a structured QOL diary completed at home each week for 16 weeks. Patients were encouraged to share the OOL information with health professionals involved in their care but only 23% did so. At 2 and 4 months the diary group had a poorer QOL in many domains and less frequent improvement. No effects were found in relation to satisfaction with care, communication, or the discussion of patient problems. The authors concluded that QoL home screening without systematic follow-up was not beneficial and potentially even harmful.

Results were compared with treatmentas-usual. Radiotherapists were trained in using and interpreting the SIPP, including interpretation of scores and the type of potential psychosocial problems and the need for psychosocial care during a onehour training session. At baseline, 263 patients completed the SIPP screening and 250 completed repeat SIPP screening and outcome measures at end of their radiotherapy treatment. While results have yet to be fully reported, acceptability of the screening to patients appears high; however reception by radiotherapists was mixed. 63.6% (21/33) who screening positive accepted psychosocial care. Carlson et al., examined the effect of screening on the level of psychological distress in lung and breast cancer patients randomized to minimal screening (no feedback), full screening (with feedback) or screening with optional triage and referral⁽³⁵⁾. The guestionnaires used were the EORTC QLQ-C30 and a touch-screen version of the HADS. This was one of the largest studies to date with over 1000 patients, 365 in minimal screen, 391 in full screen and 378 in screening with triage. Results differed by cancer type. In lung cancer patients receiving full triage, 20%

fewer reported continued high distress at follow-up compared to other groups. In breast cancer the full screening and triage groups both had lower distress at followup than minimal screening. A positive effect on emotional well-being was seen in the intervention vs control group but there was little to differentiate intervention and the screening-only attention-control. Although more frequent discussion of chronic non-specific symptoms was found in the intervention group (without prolonging encounters), there was no detectable effect on patient management. Clinician satisfaction was also monitored prospectively. Physicians found the HRQL information clinically "very useful/quite useful" in 43% of encounters, "somewhat useful" in 28%, "little useful" in 21%, and "not useful" (or missing response) in 9%. They felt that the HRQL screening data provided additional information in 33% of cases and identified problems for discussion in 27%. By physician report the screening summary contributed to patient management in only 11% of encounters.

Carlson et al., also conducted a large scale 2-arm RCT of computerized screening (in which patients received a printout summary of concerns and instructions on how to access appropriate services) versus personalized screening (wherein patients received a brief computer printout summary of concerns and were contacted by a screening team member within 3 days⁽³⁶⁾. There were no significant differences in HRQoL and treatment satisfaction outcomes between any groups at 3 and 6 months, although high baseline scores may have made improvements difficult to produce.

Braeken et al., conducted an innovative study using radiotherapists who were asked to apply a 24-item Screening Inventory of Psychosocial Problems (SIPP) and indicate whether patients were offered an appointment with a psychosocial care provider⁽³⁷⁾. Results were compared with treatmentas-usual. Radiotherapists were trained in using and interpreting the SIPP, including interpretation of scores and the type of potential psychosocial problems and the need for psychosocial care during a onehour training session. At baseline, 263 patients completed the SIPP screening and 250 completed repeat SIPP screening and outcome measures at end of their radiotherapy treatment. While results have yet to be fully reported, acceptability of the screening to patients appears high, however reception by radiotherapists was mixed. 63.6% (21/33) who screening positive accepted psychosocial care.

Klinkhammer-Schalke for the Regensburg QoL Study Group randomized 200 representative breast cancer patients to receive either notification of low QoL (with a report sent to the patient's coordinating practitioner), or standard postoperative care adhering to the German national guideline for breast cancer⁽³⁸⁾. Patients were followed for 6 months after surgery. Low QoL was present in 56% of the intervention group at 6 months (especially in emotion and coping domains), compared with 71% in controls, a significant difference favouring screening.

Finally, Hollingworth et al., used the Distress Thermometer (DT) and problem list to rate distress and discuss sources of distress as applied by a trained radiographer/ nurse and compared this with treatment as usual⁽³⁹⁾. Psychological distress (POMS-SF) and disease specific quality of life (EORTC-QLQ C30) were measured at baseline, 1 and 6 months. 220 patients (49% breast, 27% urological, 24% other cancer sites) were randomised with 107/112 in the DT arm. Both groups improved by 6 months and there was no evidence that patients randomised to the screening condition had better outcomes. Results pertaining to uptake of resources have not yet been reported.

Non-Randomized Studies

Taenzer et al., conducted a cohort study, sequentially recruiting 57 patients first into a control group, then to the experimental group⁽⁴⁰⁾. The usual care control group completed the EORTC QLQ-C30 paper version after the clinic appointment, while the experimental group completed the questionnaire before their first clinic appointment with feedback to staff. There was no difference in the number of QoL items endorsed in the intervention group but there was more discussion of QoL items during consultations, and medical records also had a greater number of QoL actions recorded with screening and feedback. Patients reported being equally satisfied with the treatment in both groups but more quality of life issues were identified by the intervention patients (48.9% vs 23.6%).

Boyes et al., asked 95 patients to complete a computerized screen assessing their psychosocial well-being while waiting to see the oncologist during each visit⁽⁴¹⁾. Alternate consenting patients were assigned to an active group with feedback and a control group without feedback. Responses (including the HADS scores) were placed each patient's file for oncologist's in attention. At subsequent visits there was no effect on levels of anxiety, depression and perceived needs among those who received the intervention, but only three intervention patients reported that their oncologist discussed the feedback report with them. Nevertheless, acceptability of the screening seemed high.

Bramsen et al., studied 50 newly admitted patients given usual care and 79 screened with the EORTC QLQ-C30, General Health Questionnaire (GHQ-12) and Impact of Event Scale (IES). They also studied a retrospective medical records group $(n=89)^{(42)}$. Referral and access to psychosocial care was the main outcome. Psychosocial care was received by 24% in the screening group, 18% in the medical records group and only 8% in the usual care group. Further, subscales on both the QLQ-C30 and the GHQ-12 significantly favoured screening over usual care.

Hilarius et al., also used a sequential cohort design to follow 219 chemotherapy patients over 4 consecutive outpatient visits⁽⁴³⁾. This was one of the largest studies to date with over 1000 patients, 365 in minimal screen, 391 in full screen and 378 in screening with triage. Results differed by cancer type. In lung cancer patients receiving full triage, 20% fewer reported continued high distress at follow-up compared to other groups. In breast cancer the full screening and triage groups both had lower distress at follow-up than minimal screening.

Thewes et al., allocated newly diagnosed patients with malignant disease to screening (n=43) with the Distress Thermometer and short Somatic and Psychological Health Report Short form (SPHERE) prior to consultation / chemotherapy education session and in high scorers nurses were encouraged to assess and manage distress⁽⁴⁴⁾. 40 historical patients followed up prior to screening acted as controls. At 6 months participants in the screened cohort reported significantly higher levels of overall unmet needs, psychological needs, information needs and physical and daily living needs compared with the unscreened cohort. This might be because screening identified a more unwell cohort or because screening was not linked with successful treatment. In fact, of those scoring \geq 5 on the DT, only 10 (53%) were referred to a social worker or psychologist. Also there was a trend (non-significant) towards lower SPHERE cases in unscreened patients vs screened (24% vs 35%, P = 0.282). Referral delay was shorter in the screened cohort (5 vs 14 days). Acceptability to patients was

generally high, as 86% did not believe that the screening questions were too personal or upsetting.

Shimizu et al., used retrospective cohort analysis of 491 patients treated during the program-period vs 574 historical control data gathered during the usual careperiod⁽⁴⁵⁾. There were significant decreases in all distress-related outcomes over time in both groups but no differences between groups. Nevertheless, patients in the personalized triage group and patients with higher symptom burden were more likely to access services, which was subsequently related to greater decreases in distress, anxiety and depression.

Grassi et al., used a retrospective cohort analysis of 583 patients treated during the intervention period compared with 153 historical controls⁽⁴⁷⁾. Screened patients received the Distress Thermometer and associated problem list. Screening increased referrals to a specialist psycho-oncology service from 6.1% to 25.7%. Patients who screened positive and were referred to services had higher distress scores, suggesting the programme focussed attention on those with more emotional needs.

Mitchell et al., carried out a retrospective cohort analysis of 379 patients screened using the Distress Thermometer or Emotion Thermometers compared against the same patients acting as historical controls prior to screening⁽⁴⁸⁾. Screening took place over 15 months, unusually, as part of routine clinical care in chemotherapy suite and radiotherapy. Results showed no significant beneficial effect on detection of distress. Further, satisfaction from clinicians was mixed. Clinicians felt screening was useful during 43% of assessments, not useful in 36% of assessments and were unsure or neutral in 21%. Variables associated with high staff satisfaction were receipt of prior training, talking with the patient about psychosocial issues and improved detection of psychological problems. A favourable perception of screening was also linked with a change in clinical opinion suggested that staff who are more engaged with screening are more likely to benefit from it.

Summary of Evidence

From the 21 studies published to date what does the evidence suggest regarding the merits of distress screening in cancer settings? Only six of the RCTs actually reported direct benefits (five as a direct result of screening), although an additional 8 nonrandomized studies showed partial benefits. Only four studies scrutinized screening for unmet needs as an add-on to screening for distress^(30,38,41,44). Benefits appeared to be more significant in those depressed at baseline⁽³⁰⁾, in those followed frequently⁽²⁹⁾ or given linked input for unmet need(38) and possibly in lung cancer^(29,34). Looking at the design of these implementation studies, six were randomized application of the screening tool itself whilst the remainder randomized feedback of the results. Contrary to expectations, both Velikova et al.(32) and Carlson et al.⁽³⁵⁾ found that screening without feedback of results to clinicians appeared to be more beneficial than no screening at all. However this is contradicted by Sarna⁽²⁹⁾ and McLachlan et al.⁽³⁰⁾ who found screening with feedback was more beneficial than screening without feedback, Mills et al. who found screening without feedback was potentially harmful⁽³⁴⁾ as well as three studies showing no benefit of feedback at all^(31,33,41). It is worth highlighting that some studies compared standard feedback with enhanced (personalized) feedbak(36) and many studies varied on what intervention(s) followed screen positive results⁽³⁶⁾. From the non-randomized studies, most benefits were in the areas of communication, clinician behaviour / referral. Overall, five studies reported screening helped with patient-clinician communication^(31,32,40,43,48). Four studies noted a benefit on referral rates

or referral delay⁽⁴⁴⁻⁴⁷⁾. However, even with screening, referral rates did not exceed 25% thereby allaying concerns that screening would lead to an excess of referrals to specialist services.

A key lesson from the studies so far, is the effect on acceptability to either clinicians or patients. Several studies have reported that under optimal conditions (generally funded screening programmes) it is possible to screen large numbers of patients with few refusals. For example Carlson et al. accrued 89% of all eligible patients in lung and breast cancer clinics over an 18 month period⁽³⁵⁾. Shimizu et al., similarly accrued 92% of cancer patients in a general oncology practice⁽⁴⁵⁾ and Ito et al recruited 76% of eligible chemotherapy patients⁽⁴⁶⁾. Large screening programmes are often assisted by computerized touch screen terminals. Two RCTs reported on acceptability. Velikova (2004) monitored physician satisfaction with screening prospectively⁽³²⁾. Physicians found the HRQL information clinically very useful/quite useful in 43% of encounters but only somewhat useful in 28% (30% thus reported little use). Braeken et al. found that reception by radiotherapists in a more clinically representative setting was mixed⁽³⁷⁾. Only 32.5% of a total of 889 potentially eligible patients agreed to participate but two thirds of those who screened positive accepted psychosocial care. Similar results were reported by Mitchell et al., who assessed implementation of a simple visualanalogue screener without assistance in routine cancer care⁽⁴⁸⁾. After 379 screening applications, clinicians felt screening was useful during 43% of assessments, not useful in 36% of assessment and were unsure or neutral in 21%. Over a third felt that the screening program was impractical for routine use (38%) and more chemotherapy nurses than radiographers rated the screening program as "not useful" (43% vs 22%).

Thus despite much success of programs

with dedicated staff, there is still a need more research investigating for the practicalities of adopting screening for distress programs in real-life clinical practice using existing staff. This is important because studies suggest that staff training and "buy-in" may be essential components for successful screening for distress programs^(37,44,47,48). Staff application of screening results for the intervention group was described in only three studies and two of these studies showed poor use. Boyes et al., found only three patients in the intervention group who reported that oncologists had discussed their results with them⁽⁴¹⁾, and Velikova et al., found that oncologists used the screening results in only 64% of third sessions⁽³²⁾. Only Maunsell et al., reported positive use, in the form of a social worker who contacted and visited 91 screen positive patients⁽²⁸⁾. Finally, only three studies commented on screening patients with advanced cancer^(29,34,48) and none were conducted in palliative settings, despite a large literature on diagnostic validity of screening tools in this group^(22,24).

DISCUSSION

Previous work has largely focussed on the development and diagnostic validity testing of tools for measuring cancer-related distress. Despite strong recommendations of many professional societies and accreditation agencies, to date very few cancer centres have adopted routine screening for distress or unmet needs assessment^(55,56). For example out of 84 Canadian cancer institutions 36.5% routinely screened patients for emotional distress at the time of admission⁽⁵⁶⁾. The evidence-base for distress screening is by no means over-whelming and has been limited by methodological considerations. Screening for emotional complications has often focussed on depression. Screening for depression, although important, cannot cover all the emotional complications that patients experience. Many groups have tended to overlook evaluation of unmet needs and practical concerns, clarification of a desire for help and the acceptability of the treatment offered. These may be essential steps in determining the effectiveness of screening. In our analysis, only six of twelve (50%) of randomized but 7 of 8 nonrandomized trials showed a positive effect on psychological well-being. Regarding acceptability, programmes appear to show enhanced acceptability when assisted by dedicated funded trials staff. In clinical settings it is not certain whether systematic screening can actually be accomplished in busy clinical environments. Systematic screening holds the appeal of broad detection but the key question is whether such a generalized screening program would be acceptable to both patients and front-line cancer clinicians.

An alternative is targeted screening of pre-selected high risk groups, such as those with troubling physical complication or those people whose family members ask for help. Targeted screening is theoretically more efficient than systematic screening because the prevalence of the condition under study is higher and hence fewer screens are needed for each identified case. In addition, psychosocial treatment is more successful when the baseline severity is high⁽⁵⁷⁾. However this has the risk of immediately overlooking many with unmet needs in low risk groups.

For widespread use in clinical practice, tools that take less than 2 minutes to apply are preferred, especially when trained mental health specialists are not available^(58,59). Currently, the most popular short tools for screening for distress are visual-analogue scales. which include the 'distress thermometer', the 'impact thermometer' the 'emotion thermometer'. The and Distress Thermometer appears to be a reasonably accurate rule-out method comparison with interview-defined in distress⁽²²⁾ and can easily be supplemented with additional domains with no undue increase in complexity^(60,61). Visual-analogue scales are usually highly acceptable, but the completion rates may be lower than with verbal or categorical scales⁽⁶²⁾. Certain patient groups may struggle in completing self-reports, particularly those with visual problems, severe fatigue or cognitive impairment; language and cultural barriers must also be considered. A brief alternative to visual-analogue methods is simple verbal query, although surprisingly no studies have been conducted to validate it against distress in cancer patients. A comparison of these methods suggests that their accuracy is similar, although there has been no wellpowered comparative research.

А distress management plan is important to ensure that staff systematically acts on screening results; it also implies that the health-care system has resources for handling distress. A positive screening should be followed by thorough clinical assessment and competent management⁽⁶³⁾. Depending on the needs identified for specific populations, the actions that screening could involve, follow for example, a stepped approach, ranging from group-based psycho-education for people with mild-moderate distress to structured individual therapy for those with high distress. However not all patients identified as being distressed are interested in professional support^(64,65). Carlson et al., reported that less than one third of patients found to be distressed on screening accepted referral for psychological support⁽³⁵⁾. Other surveys have reported that only 10% of unselected patients and 40% of distressed patients wanted further professional help⁽⁶⁶⁾.

Several barriers to implementation should be acknowledged. A survey of UK cancer health professionals suggested that the main barriers to successful screening, besides lack of time, were insufficient training and low confidence⁽⁶⁶⁾. Our analysis of the randomized and non-randomized trials suggests that future studies should attempt to quantify and address these barriers. Future studies should also use representative samples, offer staff training and track staff and patient use of subsequent interventions. New trials addressing some of these methodological issues are currently underway in oncology settings but few if any have been conducted in palliative care. Successful distress screening tools could be incorporated into screening programmes that also contain elements for measuring unmet needs, desire for help, clinical responses and longitudinal outcomes and perhaps will then be seen as part of essential cancer care.

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