Screening for need or needing to screen?

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Aims

To:
Present overview of current discussion regarding the contribution of psychosocial needs screening in cancer - in the growing context of a mandate to screen

To:
Discuss findings from an analysis of supportive care needs screening data collected at the Peter MacCallum Cancer Centre (PeterMac) between July 2011 and June 2012.
The debate

“They refer to distress screening guidelines published by the National Comprehensive Cancer Care (NCCN) – they did not provide evidence from RCTs that patients screened using the NCCN paradigm have better health outcomes that patients not screened”

Questioning screening for distress …..“contravenes recommendations, based on prevalence studies demonstrating that patients experience distress in physical, psychological and practical domains, with a real interplay between domains”

Thombs and Coyne, J Psychosom R, 2013

Bultz et al, JNCCN, 2013
The mandate

Routine screening for distress (whether generalised distress due to supportive care needs or psychological distress) is recommended as best practice in several international Guideline documents.
International Guidelines

• National Institute for Clinical Excellence (NICE): Guidelines on Cancer Services. Improving Supportive and Palliative Care for Adults with Cancer – UK, 2004

• Institute of Cancer Medicine (IOM): Cancer Care for the Whole Patient. Meeting Psychosocial Health Needs. IOM, USA - 2007

In Canada:
The Canadian Strategy for Cancer Control (2004), added distress as a new vital sign - embedding screening into routine clinical practice.

Feasibility?
Cost efficiency?
Does it make a difference to patient outcomes?
In Australia

In **New Zealand**, The Ministry of Health document: *Guidance for Improving Supportive Care for Adults with Cancer* (2010), advocates for access to supportive care throughout the stages of cancer.

NHMRC
Up until recently the debate about the state of the knowledge regarding the efficacy of screening has largely been silent.
But no more…

“..routine screening for distress has the potential to help practitioners identify and manage the psychosocial, practical and physical concerns that may contribute to distress”

Bultz et al, JNCCN, 2013

“..too early to conclude definitively that screening itself affects the psychological wellbeing of cancer patients”

What do we mean by screening?

Medical definition

screening is defined as an intervention that involves application of a screening tool or process to individuals otherwise unaware they are at risk, but amenable to and results in receipt of an intervention

“Choosing Wisely Campaign”

26 US hospitals have each listed five commonly used tests or procedures that should be questioned by doctors and patients
But in the context of distress…

A definition of screening is more complex.

We lack evidence to demonstrate that screening results in identifying those currently not being identified but who have capacity to benefit.

For example,

Is giving someone a questionnaire to inform care consultations screening - when information gathered may not result in receipt of an intervention?
What is the problem? Do we need to screen

*Chambers et al, EJCC, 2012*
53.4% of patients (n=354) with lung cancer who called a cancer helpline reached caseness in anxiety, depression or somatization (Distress Thermometer, Brief Symptom Inventory, Impact of Events Scale)

*Ugalde et al, Support Care Cancer, 2012*
39.8% of patients (n=108) with lung cancer reported distress above cut-off on the distress thermometer

*Beesley et al, Psychooncology, 2008*, 802 women with gynaecological cancers – 43% had at least one moderate or high level unmet need

Population based cohort of 3439 adult cancer patients. 40% had unmet physical needs and 37.5% had unmet emotional needs (EORTC QLQ –C30 and Profile of Mood States)
Psycho-Oncology

Psycho-Oncology 21: 1027–1033 (2012)
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Editorial

Psychosocial care in cancer: an overview of psychosocial programmes and national cancer plans of countries within the International Federation of Psycho-Oncology Societies

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†See Appendix A for complete list of collaborators and co-authors.

Abstract

We report data from representatives of national professional psycho-oncology societies on the integration of psychosocial care into national cancer programmes or cancer plans. To date information on how, or whether, psychosocial care has been recognized and integrated into comprehensive cancer care internationally has been extremely limited. The value of the current survey, whilst not comprehensive, lies with the fact that it is the first to report on the current status of psychosocial care for cancer patients and their families from a global perspective.

Representatives of 29 countries that are members of the Federation of National Psycho-Oncology Societies, coordinated under the aegis of the International Psycho-Oncology Society (IPOS), participated in a survey aimed at clarifying access to psychosocial care. Results indicate that while psychosocial oncology has grown over the last decade, it is either not established or not completely established, or not an integral part of care in some countries, especially developing countries, where basic care is sometimes not provided to cancer patients.

Future targets need to focus on the integration of psychosocial oncology programmes into comprehensive cancer care and their coordination within multidisciplinary teams.

Received: 4 July 2012
We lack a gold standard tool to screen for distress in patients, family/significant others

- Brief Symptom Inventory
- Hospital Anxiety and Depression Scale (HADS)
- Supportive Care Needs Survey - SF
- ** Distress Thermometer over-diagnoses prevalence
Increasing evidence that the heightened distress reported by cancer patients is self-limiting or resolves within routine cancer care without speciality or mental health services.

Rate of overall decline in distress in routine care dwarfs any differences among conditions in screening studies.

Of the patients with persistent distress, the majority have prior problems or non-cancer related problems.
Effects of screening for psychological distress on patient outcomes in cancer: A systematic review

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l Health Psychology Section, Department of Health Sciences, University Medical Center Groningen, University of Groningen, The Netherlands
The Review

*Review question 1:* What are the effects of interventions to reduce distress among cancer patients who have been selected for treatment based on a minimum threshold of psychological distress?

*Review question 2:* Is routine screening for psychological distress of cancer patients more effective than usual care in reducing symptoms of distress?
Of 4,167 unique citations

14 eligible RCTs for treatment of distress

Treatment of distress with pharmacological or behavioural interventions shown to improve psychological distress in adult cancer patients with psychological distress

1 RCT on the effects of screening on patient distress:

A study of monthly, telephone screening for psychological distress for newly diagnosed women with breast cancer, did not improve psychological distress (Maunsell et al, JCO, 2006)
Other reviews have reported similar conclusions – but are less critical of the need to continue screening….


But there is always a counter argument

Implementing routine screening for distress, the sixth vital sign, for patients with head and neck and neurologic cancers (Bultz B et al, JNCCN, 2013)

A comparative, 2 cohort, pre-post implementation, sequential design study

Cohort 1 pre implementation of screening and cohort 2 a year later post implementation

Measures: ESAS and the Canadian Problem checklist; FACT-Brain; FACT- Head and Neck
Findings:

Patients in Cohort 2 showed significant improvements on emotional quality of life subscales of FACT.

Authors concluded: patients exposed to routine screening for distress reported better well-being and fewer emotional, physical and practical problems than historical controls.
And so what do we conclude?

Finding a balance to move forward….The next research opportunity

No trials have found that patients who undergo screening have better outcomes than patients who do not .. NOT WHEN THE SAME TREATMENTS ARE AVAILABLE

Screening must be delivered as part of a functional, coherent system of care, moving from identification to follow up
Patterns and predictors of supportive care referrals in ambulatory oncology patients in Victoria, Australia

Karla Gough, Allison Drosdowsky, Sibilah Breen and Mei Krishnasamy

The Department of Cancer Experiences Research
Background and aim

• Background
  – improving the identification and management of supportive care needs is a core component of Victorian supportive care policy

  – routine capture and storage of patient-reported supportive care needs data and clinician-reported referral data supported the linking of patient needs and referral data to other data stored in the electronic medical record

• Aim
  – to identify patterns and predictors of supportive care referrals in formally screened ambulatory cancer patients
Methods

• Retrospective audit and analysis of electronic screening and medical records data for formally screened ambulatory cancer patients attending Peter Mac between July 2011 and June 2012

• Most data was captured from electronic databases

• Patient responses to the Supportive Needs Screening Tool Forms (Initial Screening form and clinician responses Referral form)
  – age, sex, marital status, preferred language and tumour stream

• Data gathered via an audit of each patient’s electronic medical record
  – Supportive care appointments attended
  – Postcode, disease stage and time since diagnosis
Supportive Needs Screening Tool

The diagnosis and treatment of cancer affects many parts of life. We care about all aspects of your well-being, not just your physical health. We would therefore like to ask you some questions about your health and how you are feeling. Your answers to these questions will help us to offer you the most appropriate care.

Instructions
Please read each question and choose the answer that best reflects your situation. If you have any questions or concerns about completing this form then please feel free to discuss this with the nurse caring for you.

Date: ___ / ___ / ___

1. Do you need some help understanding English?  
   ○ No  ○ Yes
2. Do you need some help understanding written English?  
   ○ No  ○ Yes
3. Are you of Aboriginal or Torres Strait Islander origin?  
   ○ No  ○ Yes
4. Do you have a disability or a chronic illness?  
   ○ No  ○ Yes
5. Do you have any difficulty with concentrating or remembering things?  
   ○ No  ○ Yes
6. Do you have any difficulty with hearing?  
   ○ No  ○ Yes
7. Do you wear a hearing aid?  
   ○ No  ○ Yes
8. Do you have any difficulty with seeing?  
   ○ No  ○ Yes
9. Do you wear glasses or contact lenses?  
   ○ No  ○ Yes
10. Do you usually use any type of mobility aid?  
    ○ No  ○ Yes
11. If you use health or mobility aids please select which aids you use from the list below.
    ○ Walking stick, walking frame or cane  ○ Wheelchair  ○ Pseudomer  ○ Stone bag  ○ Other (please specify)
12. Have you had a fall in the past 3 months?  
    ○ No  ○ Yes
13. During the past 2 weeks did poor health interfere with your activities?  
    ○ No  ○ Yes
14. In the past two weeks have you had any of these health concerns for more than a few days?  
    ○ Feeling sick or nauseous  ○ Vomiting  ○ Headache or dizziness  ○ Lack of appetite  ○ Difficulty swallowing  ○ Difficulty losing weight  ○ Difficulty with your bowels (e.g. constipation or diarrhea)  ○ Difficulty with passing water (e.g. bladder control, pain, catheter)  ○ Problems with your mouth (e.g. ulcers, bleeding gums, infection)  ○ Problems with your skin (e.g. brown marks, skinning or burning, pressure resulting in bed sores)  ○ Weakness in arms or legs  ○ Decrease sexual interest  ○ Decrease in energy  ○ Fatigue, tiredness or lack of energy  ○ Feeling short of breath  ○ Feeling fatigued  ○ Other what?  ○ I have had no health concerns

Example

15. How often do you have a drink containing alcohol?  
    ○ 0-4 times a week  ○ 0-1 times a week  ○ 2-4 times a month  ○ Monthly or less  ○ Never
16. How often do you take recreational drugs (e.g. marijuana, amphetamines etc)?  
    ○ 0-4 times a week  ○ 0-1 times a week  ○ 2-4 times a month  ○ Monthly or less  ○ Never
17. How often do you take non-prescription medicines (e.g. vitamin, herbal preparations, Panadol etc)?  
    ○ 0-4 times a week  ○ 0-1 times a week  ○ 2-4 times a month  ○ Monthly or less  ○ Never
18. How often do you smoke any tobacco products?  
    ○ Not at all  ○ 0-4 times a week  ○ 0-1 times a week  ○ 2-4 times a month  ○ Monthly or less  ○ Never
19. During the past 2 weeks have you?  
    ● Felt sad, flat or depressed most of the time?  ○ No  ○ Yes
    ● Felt a loss of interest or pleasure in things that you usually enjoy?  ○ No  ○ Yes
    ● Felt a lot of worry or anxiety?  ○ No  ○ Yes
    ● Felt it difficult to take your mind off worrying thoughts?  ○ No  ○ Yes
    ● Existed feelings of sudden panic or fear?  ○ No  ○ Yes
    ● Felt very restless or constantly needing to be on the move?  ○ No  ○ Yes
    ● Felt generally slowed down or sluggish?  ○ No  ○ Yes
    ● Felt a need to avoid certain situations or people?  ○ No  ○ Yes
    ● Had difficulty concentrating or making decisions?  ○ No  ○ Yes
    ● Had thoughts about giving up treatment?  ○ No  ○ Yes
    ● Had thoughts about hurting yourself or suicide?  ○ No  ○ Yes
20. Has there ever been a time when you felt sad or depressed for more than a few weeks?  
    ○ No  ○ Yes
21. Have you EVER had any treatment for psychological/emotional concerns?  
    ○ No  ○ Yes
22. Are you, CURRENTLY receiving treatment for psychological/emotional concerns?  
    ○ No  ○ Yes
Supportive Needs Screening Tool
Methods

• Descriptive statistics were used to summarise patterns of:
  – referrals offered and accepted and
  – appointments attended

• Logistic regression was used to model the probability of
  being offered a referral for social work and being offered a
  referral for any other type of supportive care service
  except social work
  – final multiple regression models included age, sex,
    marital status, first language, residential location and
    disease stage, as well as other variables based on
    patient-reported needs data (included if significant in
    univariate regression models)
Other variables:

• physical & emotional health concerns

• support & coping

• desire for some/more information about diagnosis/treatment

• help with practical/financial issues

• services to support physical, emotional or spiritual needs

• services to help family/support people
Patient characteristics

- The original data included 717 patients
- 110 patients were excluded (missing data, screened outside time period of interest or repeat screening)
- 607 patients with near-complete data were included in the analysis
  - average age was 60.0 years (SD = 14.7 years; range 18 – 95 years), most were in a relationship (64%) and most lived in metropolitan Melbourne (66%)
  - patients were predominantly from the gastrointestinal (21%), urology (20%), gynaecology (19%) and breast (14%) tumour streams,
  - half had advanced disease (stages 3 and 4, 46%) and,
  - most had been diagnosed with cancer within 12 months of screening (85%)
Referrals offered and accepted

- Ambulatory cancer patients formally screened between July 2011 and June 2012 were offered 709 referrals

- Over half (n=339, 56%) were offered at least one screening-related referral (range 0 – 9 referrals)
  - 26% were offered one supportive care referral
  - 15% were offered two
  - 7% were offered three and
  - 8% were offered four or more
Referrals offered and accepted

<table>
<thead>
<tr>
<th>Supportive care service</th>
<th>Referrals offered</th>
<th>Referrals accepted</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>% of referrals</td>
</tr>
<tr>
<td>Social work</td>
<td>245</td>
<td>34.6</td>
</tr>
<tr>
<td>Nutrition</td>
<td>110</td>
<td>15.5</td>
</tr>
<tr>
<td>Clinical psychology</td>
<td>63</td>
<td>8.9</td>
</tr>
<tr>
<td>Nursing</td>
<td>42</td>
<td>5.9</td>
</tr>
<tr>
<td>Smoking cessation service</td>
<td>42</td>
<td>5.9</td>
</tr>
</tbody>
</table>

- The most common reasons for social work referrals were financial or practical issues (71%) followed by adjustment or support (36%) and counselling (28%)
- The most common reason for nutrition referral was a risk of malnutrition as indicated by standardised assessment (60%)
- Reasons for referrals to clinical psychology were poorly documented; however, where documented, worry, panic or distress was the most common reason for referral
Appointments attended

<table>
<thead>
<tr>
<th>Supportive care service</th>
<th>Visits from referral</th>
<th>Visits not from referral</th>
<th>Total visits</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social work</td>
<td>85</td>
<td>61</td>
<td>146</td>
<td>49</td>
</tr>
<tr>
<td>Nutrition</td>
<td>54</td>
<td>43</td>
<td>97</td>
<td>32</td>
</tr>
<tr>
<td>Clinical psychology</td>
<td>12</td>
<td>12</td>
<td>24</td>
<td>8</td>
</tr>
<tr>
<td>Smoking cessation service</td>
<td>6</td>
<td>4</td>
<td>10</td>
<td>3</td>
</tr>
<tr>
<td>Physiotherapy</td>
<td>8</td>
<td>64</td>
<td>72</td>
<td>24</td>
</tr>
<tr>
<td>Occupational therapy</td>
<td>7</td>
<td>30</td>
<td>37</td>
<td>12</td>
</tr>
<tr>
<td>Dental service</td>
<td>13</td>
<td>2</td>
<td>15</td>
<td>5</td>
</tr>
<tr>
<td>Pain/palliative care</td>
<td>3</td>
<td>10</td>
<td>13</td>
<td>4</td>
</tr>
<tr>
<td>Speech pathology service</td>
<td>3</td>
<td>7</td>
<td>10</td>
<td>3</td>
</tr>
</tbody>
</table>

- Random sample of 300 formally screened patients attended a total of 424 supportive care appointments – 191 (45%) of these were screening-related, 233 (55%) were not

- Most visits to physiotherapy, occupational therapy, pain/palliative care and speech pathology were not screening-related
Predictors of supportive care referrals

• Predictors of being offered a social work referral:
  – being female (p<.0001)
  – living outside metropolitan Melbourne (p<.0001)
  – having more advanced disease (p=.037) and
  – indicating a desire for some/more information about getting help with practical/financial issues (p<.0001)

While significant in the univariate models, age, marital status, physical and emotional health concerns, having someone to talk to about feelings/concerns, as well as a desire for some/more information about diagnosis or treatment and, services to support physical needs, emotional well-being and family/support did not contribute significantly to the prediction of being offered a social work referral in the multiple regression model.
Predictors of supportive care referrals

- Predictors of being offered a referral to any supportive care service except social work:
  - having a preferred language that was something other than English (p=.031)
  - having more advanced disease (p=.002)
  - reporting more physical health concerns (p=.023) and
  - reporting more emotional health concerns (p=.021)

While significant in the univariate models, sex, age, marital status, residential location, having someone to talk to about feelings/concerns, as well as a desire for some/more information about getting help with practical/financial issues, services to support physical needs, services to support emotional well-being and services to help family/support people did not contribute significantly to the prediction of being offered a referral to any supportive care service except social work in the multiple regression model.
Conclusions

• More often than not, screening leads to information provision (undertaken as part of patient-clinician interviews) and/or a brief targeted intervention administered by social workers and nurses

• Referral to specialised services for treatment-related and/or complex needs is the exception

• While associated with patients’ self-reported issues and concerns and desire for help, in all likelihood many supportive care referral decisions are made based on more detailed information derived from patient-clinician interviews
Research implications

• Sample bias and generalisability
  – who gets screened (only 784 of 2590 new patients screened)? and why?
    • time and resource constraints
    • nurses’ implicit theories and expertise

• Models based on documented information
  – what is not included?
    • information gleaned from unrecorded contacts very likely plays an important role in the identification of supportive care needs and subsequent management decisions

• management decision likely based on the severity of patients’ issues and concerns, not just their presence or absence (only the latter is indexed by the screening tool)
Clinical implications

• Timing of initial screen critical
  – period of flux and heightened distress prior to diagnosis
• Two-stage model of screening
  – stage 1: screening for brief targeted interventions for practical issues and treatment-related supportive care
    • utilise fairly simple information like patients’ place of residence, disease stage and desire for assistance, as well as disease type and planned treatments
  – stage 2: screening for physical and psychological morbidity
    • assess type and level, as well as desire for assistance
    • use robust measures
    • establish evidence-based cut-offs
    • target modifiable morbidity
Our findings in context…

A substantial proportion of cancer patients indicating unmet needs do not wish to receive services within the context of cancer care

There is more interest in physical therapy and nutrition than psychosocial and mental health services

Only a minority of patients who screen for distress subsequently receive services

Limited available data suggests that screening is not a cost-effective way of getting cancer patients into services

(Coyne, 2013; Mitchell et al, 2013; Mehnert et al, 2012)
And so.. screening for need or needing to screen?