Screening for Distress in Cancer Patients: A Step Towards Person-Centred Care

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Overview

- Distress
- Why screen for distress
- Cautions about screening
- How to screen for distress
- Implementation at St George’s Cancer Care Centre
Person-Centred Care

- treatment focus is caring for the person as a whole rather than a purely tumour focus
Vital Signs

1. Temperature
2. Pulse
3. Blood pressure
4. Respiratory rate
5. Pain – added in 1999
6. DISTRESS – added in 2004

Standard screening in medical settings
What is distress?

- Personal and physical suffering
- Distress is not a mental disorder. It is a psycho-emotional state that can be caused by non-psychological factors.
Distress

“a multifactorial unpleasant emotional experience in a *psychological*, *social*, and/or *spiritual* nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment”.

The National Comprehensive Cancer Network (2010)
“Distress extends along a continuum, ranging from common, normal feelings of vulnerability, sadness, and fears to problems that can become disabling, such as depression, anxiety, panic, social isolation and existential and spiritual crisis”

NCCN Practice guidelines in Oncology 2008
“A medical analogy is that screening for distress is like screening for high glucose, whereas identifying depression is analogous to detecting diabetes. Diabetes mellitus is only one cause of hyperglycaemia, but hyperglycaemia is a significant problem on its own.

Distress, unmet needs and related psychiatric disorders are certainly treatable conditions. 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.”

International Standards of Care (NCCN Guidelines 2013)

- Distress should be monitored and treated promptly
- Screening should identify the level and nature of the distress
- All patients should be screened at their initial visit and at appropriate intervals
The NZ Setting:

- Ministry of Health Guidelines for Supportive Care (2010/11)
- Cultural needs/considerations
Why screen for distress?

“To Identify patient distress and what is causing it and resolve the distress at the earliest opportunity, in accordance with the patient’s wishes”

James Brennan
Why screen for distress?

- Distress is common
  - Clinically significant levels of psychological distress of between 30 and 60% have been measured in oncology patients (Graves et al., 2007; Kendall, Glaze, Oakland, Hansen, & Parry, 2011; Mitchell et al., 2011).

- Patients experiencing distress are not being routinely identified.

- Psychological distress can impact on quality of life, treatment compliance and self-care.
High levels of psychological distress but low detection rates

- 143 doctors assessed the psychological status of 2297 outpatients in cancer centres all over the UK

- 36.4% of patients had scores indicative of psychiatric levels of distress

- Less than a third of these patients with high levels of stress were identified (Fallowfield et al. 2001, Br J Cancer, 84, 1011-1015)

- Only half of patients with clinically significant levels of distress sought help. (Carlson et al., 2004, Br J Cancer 90, 2297-2304)
Health Professionals

Lawrie et al. (2004), Palliat Med, 18,234.

- Multidisciplinary cancer clinicians - 63% ask about emotional problems, 37% rarely ask

- 134 doctors in palliative care setting - 70% routinely looked for anxiety and depression. Of these:
  - 50% had no formal method
  - 10% single question – “are you depressed?”
  - 27% used Hospital Anxiety and Depression Scale (HADS)
Why might this be?

Clinician Factors
- Willingness to discuss
- Lacking confidence
- Low skills re diagnosis
- Consultation time

Patient Factors
- Confidence in clinician
- Willingness to discuss personal difficulties
- Belief that help is available
Why screen for distress?

- Distress is common
- Patients experiencing distress are not being routinely identified.
- Psychological distress can impact on quality of life, treatment compliance and self-care.
Those against routine screening raise several worthwhile cautions:

- First, that screening should apply only to those not already currently recognized as depressed in receipt of treatment.
- Second, that those who screen positive often do not accept the treatment that is offered.
- Third, the same treatment and care resources should be available to both groups (screened and not-screened) to effectively isolate the effect of screening per se.
- Fourth, screening routinely may be inefficient given that many people have very mild complications.
- Fifth, screening can be resource intensive and can be a burden to staff and patients.
Caution!

Before implementing a screening programme you **must** consider how you will respond to patient needs once they have been identified.
“The proportion of cancer patients who received psychosocial care after a positive distress screen was only 20 – 30%. This shows that aftercare is probably the key rate-limiting step. Screening was more effective when screening was linked with mandatory intervention or referral.”

Mitchell (2013)
Service provision

All patients require screening, information, basic emotional support, good communication, symptom management (100%)

Patients may need additional information, education and encouragement to seek extra help (20% do well with this level)

Some will require specialised/professional intervention for symptom management (35-40% will need this level)

A few may need complex care (10-15% will require this level)

(From Guide to implementing screening for distress, 2009)
Screening Programmes

Patient centred care
Improving the quality of care
Screening vs Assessment

- Screening = rapid identification of key indicators that allow for further assessment and appropriate referral.
- Assessment = a more comprehensive and focused examination of the patient’s situation.
Who to screen?

- All patients
- Regardless of cancer type or stage
- Different populations will differ in their concerns
- Opens the door to further conversation
When to screen?

- Regular
- Routine on entry to service
- Repeat at critical time points
  - start of treatment,
  - during treatment,
  - end of treatment,
  - follow-up/transition to survivorship,
  - disease progression
Who should do the screening?

- Service-wide approach across disciplines
- “Nitty-gritty” will probably vary service to service
- The staff that interact with patients the most, Nurses, RTs, Admin?
- Physicians?
Screening modality

Pen and Paper?

- Patients are used to paper work
- Don’t need to invest in hardware
- No new space required
- Data may need to be entered into computer
- Piles of paper!
- Can decrease data integrity

Computer/touch screens?

- Most patients find computers easy to use
- Trending information can be available immediately
- Easy to evaluate programme
- Some patients will need assistance at least once
- IT support required
- Pen and paper version for patients unable to use computer
What do we screen for?

- Psychosocial
- Practical
- Physical
Top 10 concerns

Lscalzo & Clark (2007) Oncology 21, 1133-1138

1. Fatigue
2. Sleep
3. Finances
4. Pain
5. Fear and worry about future
6. Being dependent on others
7. Being anxious or nervous
8. Feeling depressed/down/blue
9. Understanding my treatment options
10. Managing my emotions
Screening tools

- 3 Questions (Informal)

1. How is your mood?
2. Are you still enjoying activities you previously enjoyed?
3. Are you experiencing any anxiety?

- Basic but reasonably effective
Distress Thermometer
1. In the first four columns, please mark the number (0-10) that best describes how much emotional upset you have been experiencing in the past week, including today. In the final column please indicate how much you need help for these concerns.


- Extreme: Desperately need help
- None: I am 100% ok

Adapted from the NCCN Distress Thermometer, Alex Mitchell ©
Emotion Thermometers

- Split into different emotions which may reflect what patients might be experiencing.
- Help thermometer – gives patients a way of saying “yes please” or “no thanks”.
- Nice visually and easy to use.
Problem List

• Problem list – way of targeting help.

• Modified using James Brennan’s adaptation. (Brennan et al., 2011, Psycho-Oncology)

• Incorporating Don Baken’s NZ adaptation. (Baken & Woolley, 2011, Psycho-Oncology)
1. If any items have been a cause of distress for you over the **past week, including today**, tick the box next to it. Please leave blank if it does not apply to you.

2. Then rank 1st, 2nd, 3rd, 4th your top 4 difficulties (1 would be the biggest problem, 4 would be the 4th biggest problem) and put this number beside the item in the **Rank** column.

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**Any other concerns:**
Bristol Study

• 735 recently discharged cancer patients from the Bristol Haematology & Oncology Centre (hospital database)

• No inclusion or exclusion criteria except...

• Excluded: those patients imminently dying (< 1 month), as judged by Clinical Trials Nurse from discharge letter
Hospital Anxiety and Depression Scale (HADS)

Name: ___________________________ Date: ___________________________

Clinicians are aware that emotions play an important part in most illnesses. If your clinician knows about these feelings he or she will be able to help you more.

This questionnaire is designed to help your clinician to know how you feel. Read each item below and underline the reply which comes closest to how you have been feeling in the past week. Ignore the numbers printed at the edge of the questionnaire.

Don’t take too long over your replies, your immediate reaction to each item will probably be more accurate than a long, thought-out response.

I feel tense or ‘wound up’
Most of the time
A lot of the time
From time to time, occasionally
Not at all

I still enjoy the things I used to enjoy
Definitely as much
Not quite so much
Only a little
Hardly at all

I get a sort of frightened feeling as if something awful is about to happen
Very definitely and quite badly
Yes, but not too badly
A little, but it doesn’t worry me
Not at all

I can laugh and see the funny side of things
As much as I always could
Not quite so much now
Definitely not so much now
Not at all

Worrying thoughts go through my mind
A great deal of the time
A lot of the time
Not too often
Very little

I feel cheerful
Never
Not often
Sometimes
Most of the time

I can sit at ease and feel relaxed
Definitely
Usually
Not often
Not at all

I feel as if I am slowed down
Nearly all the time
Very often
Sometimes
Not at all

I get a sort of frightened feeling like ‘butterflies’ in the stomach
Not at all
Occasionally
Quite often
Very often

I have lost interest in my appearance
Definitely
I don’t take as much care as I should
I may not take as much care
I take just as much care as ever

I feel restless as if I have to be on the move
Very much indeed
Quite a lot
Not very much
Not at all

I look forward with enjoyment to things
As much as I ever did
Rather less than I used to
Definitely less than I used to
Hardly at all

I get sudden feelings of panic
Very often indeed
Quite often
Not very often
Not at all

I can enjoy a good book or radio or television programme
Often
Sometimes
Not often
Very seldom

Now check that you have answered all the questions.
Other screening options

- Anxiety
  - Beck Anxiety Inventory
  - Fear of progression Scale
  - Impact of Events Scale
  - State-trait Anxiety Inventory
  - Memorial Anxiety Scale for Prostate Cancer

- Distress
  - Brief Symptom Inventory
  - General Health Questionnaire
  - Profile of Mood States
  - Psychological Distress Inventory
  - Psychosocial Adjustment to Illness Scale
  - Symptom Checklist 90

- Depression
  - Beck Depression inventory
  - Brief Case find for depression
  - CES-D
  - HIS
  - MADRS
  - MEQ
  - PHQ9
  - EPDS
  - GDS
  - SDS
“No thanks - I’m OK”

- Not all patients that score above cut off points want help
- about 1/3? decline

- When help refused reasons given include:
  - Getting help elsewhere (59%)
  - “Feel well” (43%)
  - Coping on my own (24%)
  - Afraid of side effects (8%)
  - I don’t talk about my problems (8%)

(Baker-Glenn et al, 2008)
Responding to Distress

- Discuss problem with patient
- Give written information e.g. skin care info, sleep info
- Follow up with patient at next visit
- Refer on where needed
Distress Resource Directory (Bristol)

• For every Problem List item…

• Background information
• Common management strategies
• Local and national resources for more specialist help
• Further information
Communication

- How is an individual’s distress going to be communicated to the team?
- What amount of detail?
Effectiveness

- 17 of 24 screening implementation studies show that there are some statistically significant benefits of screening on primary or secondary outcomes.

- Across all studies, barriers to screening success were significant.

- At the clinician level the main barriers to screening are lack of time, lack of training and low personal skills or confidence.

- At the organizational level, barriers include lack of resources and the absence of a screening strategy.

- In short, screening success may be determined by two key factors: acceptability and resources.

Mitchell (2013)
St George’s Cancer Care Centre
Which screening tool for the Cancer Care Centre?

- Something to fit with the needs of patients and staff
- Not too long but not too short
- Needed to have clinical utility
Problem List plus 5 ETs

- Can fit on one page but using two pages for ease of use.
- Does require reading ability
- 5 to 10 minutes to complete.
- Can be filled out while waiting to be seen.
Implementation

- Staff were motivated.
- Education session.
- RT liaison.
- Admin support.
- Trial and error of best way to administer.
- **Goal is for screening to become part of standard care.**
Procedure

- Administered by RTs, chemo nurses, at beginning, middle and end of treatment, and by admin staff for follow ups.
- Forms scanned into notes.
- RTs and nurses check completed forms so can address any problems with patients.
- Looking for scores 4 and above.
- Patients asked if they would like help, response is documented in patient notes.
- Forms with elevated scores are then checked by psychologist.
Results: first 50 patients

- high completion rate
- 44% women, 56% men
- 41-84 years old
- 96% NZ European/Pakeha, 4% other European
- Mostly breast or prostate, some bowel or head and neck
- 6% palliative
• 9 patients scored above cut off for distress,
• of these 8 had between 1 and 4 sessions with Clinical Psychologist
• 1 declined appointment.
• Problems addressed included, anxiety, sleep, low mood/depression, talking about cancer with family, fatigue, relationships, body image
• No false positives
• ? False negatives
Feedback from RTs

- “Most people say yes but we are OK with people saying no”
- ”A place to start talking”
- “Doesn’t point people out as being different”
- “Nice to have a structured way to approach patients”
- “Helps us to support the patients better”
Feedback from RTs

- “Can pick up on things physical and emotional”
- “Has helped to identify people who don’t show their distress outwardly”
- “Nice way of following people so we can pick up on changes”
- “Can be frustrating when the screening shows distress but patients are reluctant to accept help.”
- “Admin issues sometimes”
In Conclusion

- It is both desirable and feasible to screen patients for distress in an oncology setting.
- Formal screening helps staff treat the whole person and normalises the process for patients.
- Cooperation from clinical staff including RTs, nurses, oncologists and admin staff is essential.
- Imperative to plan how you will respond to patients reporting high levels of distress.
- Need different levels of response depending on nature of problem and intensity of distress.
References


  http://www.psycho-oncology.info/index.htm


  http://www.partnershipagainstcancer.ca/wp-content/uploads/2.4.0.1.4.5-Guide_CJAG.pdf