Do cancer patients get the psychosocial care they need?

Continuing Cancer Care Conference

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UK
Do cancer patients get the psychosocial care they need?

1. What psychosocial problems do cancer patients have?

2. How can we find out who has psychosocial problems?

3. After asking what next?

4. One model for providing the psychosocial care cancer patients need.
What psychosocial problems do cancer patients have?

Making adjustments

- Fear
  - uncertainty
  - loss of control
  - trust in your own body
  - death
- Change in role
  - at home
  - at work
  - at play
  - in relationships
- Pain
- Body image
- Disability
- Loss of independence
- Money

Diagnosis
On follow-up
Recurrence
Living with chronic cancer
Palliative care
Living beyond cancer

UNIVERSITY OF LEEDS
What psychosocial problems do cancer patients have? Prevalence of distress

<table>
<thead>
<tr>
<th>Location</th>
<th>Emotional distress</th>
<th>Anxiety</th>
<th>Depression</th>
</tr>
</thead>
<tbody>
<tr>
<td>Australia</td>
<td>Pasco et al 2000</td>
<td>31%</td>
<td>11%</td>
</tr>
<tr>
<td></td>
<td>(n=504)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>UK</td>
<td>Strong et al 2007</td>
<td>22%</td>
<td>23%</td>
</tr>
<tr>
<td></td>
<td>(n=3071)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>USA</td>
<td>Zabora et al 2001</td>
<td>35%</td>
<td>24%</td>
</tr>
<tr>
<td></td>
<td>(n=4496)</td>
<td></td>
<td></td>
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</tbody>
</table>

Associated with

- Age (younger)
- Gender (female)
- Severity of disease
What psychosocial problems do cancer patients have?

Social difficulties

“I think he just shut himself off in his own little shell.”

“The business is faltering in all honesty, down to the illness….and how can I get out of the business without getting into a load of debt?”

“..I’ve got used to his cooking – at first (laughs) it were shocking, but he’s done his best..”

Wright EP et al. 2002
What psychosocial problems do cancer patients have?

Unmet needs

**Needs assessment tools**
“gap between experiences of services patients receive and those they perceive they need”

- Supportive Care Needs Survey (SCNS)
  - Psychological
  - Physical
  - Health system
  - Information

- >1000 participants
- treated with curative intent
- end of treatment & 6 months after
- Severity
- Number of moderate/severe unmet needs

*Armes et al 2009*
What psychosocial problems do cancer patients have? 

**Unmet needs**

<table>
<thead>
<tr>
<th>SCNS unmet need item (moderate or severe)</th>
<th>End of treatment</th>
<th>6 months later</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fears about the cancer spreading</td>
<td>30%</td>
<td>26%</td>
</tr>
<tr>
<td>Concerns about the worries of those close to you</td>
<td>26%</td>
<td>19%</td>
</tr>
<tr>
<td>Uncertainty about the future</td>
<td>26%</td>
<td>20%</td>
</tr>
<tr>
<td>Worry that the results of treatment are beyond your control</td>
<td>22%</td>
<td>17%</td>
</tr>
<tr>
<td>Lack of energy/tiredness</td>
<td>21%</td>
<td>19%</td>
</tr>
</tbody>
</table>

• 2/3\(^{rd}\) had no or few unmet needs at end of treatment

• 1/3\(^{rd}\) had ≥ 5 unmet moderate/severe unmet needs

• Fear of recurrence predicted on all SCNS domains except physical & sexuality

*(Armes et al 2009)*
What psychosocial problems do cancer patients have?

Unmet needs

Long term cancer survivors (≥ 5 years post diagnosis)

• > 50% reported no unmet needs

“I need help to manage my concerns about the cancer coming back”

• Most frequently endorsed unmet need (21%)

(Harrison et al 2011)
How can we find out who has psychosocial problems?

• Learn how to communicate with patients better

• Introduce screening/formal assessment
How can we find out who has psychosocial problems? Communication Skills Training (CST)

<table>
<thead>
<tr>
<th>Study</th>
<th>Finding</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Craig and Aberloff 1974</td>
<td>25% distressed none detected</td>
<td></td>
</tr>
<tr>
<td>Derogatis et al 1976</td>
<td>Over estimate anxiety under estimate depression</td>
<td></td>
</tr>
<tr>
<td>Fallowfield et al 2001</td>
<td>The doctors’ true positive rate was 29%</td>
<td></td>
</tr>
</tbody>
</table>

• Since 2004 all future cancer specialists in Britain are expected to receive CST

• Consensus meeting for European experts organised by the Swiss Cancer League on CST – *a position paper* *(Stiefel et al. 2009)*
How can we find out who has psychosocial problems? Screening/formal assessment?

FACT-G changes overtime

-4
-2
0
2
4
6
8
10
Baseline 1-3 months 4-5 months after 6 months

FACT-G difference (score over time - score at baseline)

Intervention Attention-control Control

• Patients had improved well-being in the intervention arm
• Consultation times not increased
• No greater referral for specialist help
• More discussion of non specific symptoms

Velikova et al 2004

Doctors

Nurses

• Communication: intervention arm more quality of life issues discussed
• Awareness of problems: greater awareness in intervention arm post baseline
• Patient management:
  • more written in medical notes in intervention arm,
  • no difference in prescribing, tests or referrals
• Quality of life: no difference reported by patients

Hilarius et al 2008
How can we find out who has psychosocial problems? Screening/formal assessment- acceptability

‘... if you filled that out and you did have a problem, may be you are having... like a little cry for help... but you daren’t go and say something... ...and for somebody else to come back to you and say, can we have a word with you about this... you know, it might be a really good thing...

Patient ID 14

I think it would help… because I think you pick up on some many of the points, hopefully, when you are talking to patients but… if you’ve got that information then sometimes that goes in a bit deeper than… and you can say, you mentioned this so how do you feel about it, or… you’ve got problems …

Staff ID 17 (nurse)
After asking what next? Discussion with the patient

A Framework for understanding the psychosocial response to cancer

- Past experience of cancer
- Individuals coping responses to stressful situations
- Length & Intensity of treatment
- The type of cancer: Stage, Diagnosis, Prognosis
- Age and stage in life cycle
- Disability as a result of disease and treatment
- Education
- Current situation
- Employment status
- Financial
- Home environment
- Social support

Adapted from Lauria et al (2001) Social Work in Oncology: Supporting survivors, families and Caregivers, American Cancer Society
After asking what next? Models for intervention

A tiered intervention model for psychosocial care

Adapted from Hutchinson et al 2006

A hierarchy of intervention for social difficulties

Wright et al online 2010
After asking what next?
National & international recommendations
One model for providing the psychosocial care cancer patients need

Electronic data capture
Standard assessment tools
Linked to electronic patient record (EPR)
Serial output of assessments
Outpatient nurse discusses assessment with patient
Plans for psychosocial supportive care agreed and acted on
Documented in EPR
One model for providing the psychosocial care cancer patients need: tips for implementation

- Communications skills training
- Fit in with existing roles and responsibilities
- Use electronic systems if you can
- Chose clinically meaningful assessment tools
- Train staff on
  - use of technology
  - interpretation of scores
  - recording activity
- Provide information (paper or web-based)
  - for staff
  - for patients
- Provide staff with interventions/referral pathways
- Get feedback from patients, carers and staff
Psychosocial care
Challenges to implementation

• Time
• Roles
• Resistance to change
• Privacy
• Lack of skill / expertise
• Lack of knowledge about information and support
• Lack of management strategy
• Access to specialist services
• Support for staff
Do cancer patients get the psychosocial care they need?
Sometimes and it should get better

Thanks to the MAP Foundation for permission to use their images from the series of paintings by Michele Petrone
The emotional cancer journey
http://www.mapfoundation.org/ecj.html