



SUPPORTIVE CARE SCREENING

Identifying needs for patients in the Haematology Oncology Clinic at Alfred Hospital (Alfred Health)

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SMICS Supportive Care Advisory Group and Governance Committee

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Executive Summary

Cancer remains as Australia's leading broad cause of disease burden.¹ By the age of 75 years, 1 in 3 Australian males and 1 in 4 Australian females will have been diagnosed with cancer at some stage in their life. In Victoria, more than 24,000 individuals are diagnosed with cancer each year.²

An expanding evidence base suggests more and more, the value of supportive care approaches in improving cancer experiences and outcomes.^{3,4,5}

What is supportive care?

Supportive care has been defined as care that 'helps the patient and their family to cope with cancer and treatment of it It helps the patient to maximise the benefit of treatment and to live as well as possible with the effects of the disease'.⁷

Developing the project

SMICS identified seven inter-related supportive care priorities for southern Melbourne's cancer services. Screening for supportive care needs was one of these.

The primary **purpose** of the project was to pilot an agreed supportive care screening tool to identify the needs of all new patients attending the Haematology Oncology Clinic (HOC) at The Alfred Hospital.

The Working Group considered existing supportive care screening tools, the local service provisions and possible risk factors. An adapted screening tool was developed, which incorporated the following elements:

- Distress Thermometer and Problem Checklist (validated)
- Questions addressing three risk factor areas
- Malnutrition Screening Tool (validated)
- Physiotherapy questions
- Speech Pathology questions
- Occupational Therapy questions

Project findings

The pilot screened 50 new patients (n=50).

Distress Thermometer and Problem Checklist

In this pilot, 31 out of 48 patients (2 patients did not record a distress score) or 64.6% of patients were significantly distressed (distress score of 4 or above). The average patient scored 5.

Multiple supportive care needs were experienced by patients, although the most predominant problems included fear, nervousness and worry, and loss of interest in usual activities. Fatigue, sleep and pain were most significant in the physical problem domain. This is similar across the sub-groups (distress score: 3 or less; 4 or more; incomplete). These findings support existing evidence that fatigue, anxiety and distress are often exhibited in 15-23% of patients (NBCC and NCCI 2003).

Physiotherapy questions

The pilot demonstrated that for a majority of patients (58%), falls, swelling, balance and other related physiotherapy issues were not relevant at their first appointment.

Malnutrition Screening Tool (MST)

The screening tool included three standard questions related to risk of malnutrition. The data from this pilot suggests that over 50% of patients were at either high or moderate risk of malnutrition at their initial chemotherapy appointment. This was reflected with the Problem Checklist findings.

Speech pathology questions

The specialist issues associated with speech pathology were considered by the Working Group to not often be identified at a patient's initial appointment in the HOC. The results of the pilot illustrated that for over 80% of patients, this hypothesis was correct.

Occupational Therapy questions

The OT questions related to difficulties with daily living, fatigue and anxiety, and memory or concentration issues. The results of the pilot indicated that after dietetics, OT was second in terms of identified needs and by extension, demand for referrals.

Patient survey findings

Twelve surveys were returned (24% response rate). Nearly all respondents agreed or strongly agreed that the screening tool was understandable and the words could be understood. Sixty seven per cent (67%) of respondents strongly agreed that they *felt comfortable* in answering the questions.

HOC staff feedback

The support from HOC staff was positive throughout the pilot. Feedback indicated that the level of education about supportive care, and about the screening tool itself was appropriate. Although some staff commented that the burden to complete all sections of the tool was significant for patients, the patient survey does not indicate this. Sixty seven per cent (67%) of patients who responded felt comfortable in answering the questions and found the time with staff, and opportunity to ask questions quite useful.

Recommendations

The project has demonstrated the usefulness of a supportive care screening tool for identifying referral needs in the HOC setting. The findings of the pilot reflected existing evidence about supportive care and the role that screening has in identifying patient needs from an early stage. It is recommended that:

- the findings of this pilot be considered in deliberations of the wider implementation of supportive care screening at Alfred Health, and across the southern Melbourne region
- a documented process be established within the Haematology Oncology Clinic for the screening of new patients, and the subsequent referrals required to address their needs
- the screening tool design be formalised, for inclusion in the Alfred Health medical record (and scanned medical record).
- active engagement with allied health and cancer support nurses continues, to consider service planning and information provision for patients with a new diagnosis of cancer
- consideration also be given to the translation of the agreed screening tool into several of the more predominant languages at each health service, i.e. Greek, Italian, Vietnamese
- consideration also be given to evaluating any agreed supportive care screening tool in 12-18 months time, to assess validity and feasibility of the tool across health services and across southern Melbourne.

Introduction

The Australian Institute of Health and Welfare reports that cancer remains as Australia's leading broad cause of disease burden (19% of the total).¹ By the age of 75 years, 1 in 3 Australian males

and 1 in 4 Australian females will have been diagnosed with cancer at some stage in their life. In Victoria, the diagnosis and management of cancer has a significant impact on the lives of more than 24,000 individuals who develop cancer every year, and their families.²

An expanding national and international body of evidence demonstrates the value of supportive care approaches in improving these experiences and outcomes (NBCC and NCCI 2003³, NCCN 2005⁴, IOM 2007⁵). Improving the supportive care for patients with cancer and their families is one of the four key priority areas for cancer reform in Victoria and is an action area in *Victoria's Cancer Action Plan 2008-11* (VCAP).⁶

What is supportive care?

Supportive care has been defined as care that:

.... helps the patient and their family to cope with cancer and treatment of itIt helps the patient to maximise the benefit of treatment and to live as well as possible with the effects of the disease.

(NICE 2004⁷)

Supportive care incorporates five inter-related domains of care that are given equal attention:

- physical
- social
- psychological
- spiritual
- information

Establishing the evidence

Canada leads the way internationally, with distress becoming the sixth vital sign to be checked routinely along with pulse, respiration, blood pressure, temperature and pain.⁴ In Australia, the National Breast Cancer Centre (NBCC) and National Cancer Control Initiative (NCCI) released *Clinical practice guidelines for the psychosocial care of adults with cancer* in 2003. This approach has been adopted by NICE (UK) and IOM (USA) as well. Each of these organisations has considered the role of supportive care to be integral to the treatment of patients with cancer. Below is an overview of the evidence on supportive care needs (by domain).

Table 1. Evidence relating to each of the supportive care domains

Domain	Key evidence
Physical	The most common unmet needs are fatigue, pain, nausea and vomiting, and nutritional issues. Carlson et al (2004) ⁸ reported that: <ul style="list-style-type: none"> • nearly half of all patients reported problems with fatigue • management of pain was identified as an issue in over 26% of patients
Social	NBCC and NCCI (2003) reported that: <ul style="list-style-type: none"> • financial burden, transport and accommodation, social isolation and difficulty in performing daily tasks exacerbate distress. Kim et al (2006) ⁹ notes the role of carer, in addition to other family roles, can increase the risk of mental health consequences.
Psychological	NBCC and NCCI (2003) note some of the risk factors which can contribute to increased distress associated with a cancer diagnosis: <ul style="list-style-type: none"> • younger than 55 years • lack of social supports • caring for children or other dependants • previous episodes of depression, anxiety or other psychiatric illness • high alcohol or drug intake Roth et al (1998) ¹⁰ reported that while 25% of patients exhibited significant

levels of distress, less than 10% of patients received a referral for psycho-social support.

Spiritual	NICE (2004) suggests that unmet spiritual needs may impact on a person's capacity to endure present discomforts and their ability to face their death in a way that they wish. Research indicates that spiritual issues gain more importance as physical conditions deteriorate. ⁴
Information	<p>There is also evidence to suggest that timely quality information enhances patients' psychological well-being (NBCC and NCCI 2003). Key information needs are:</p> <ul style="list-style-type: none">• about their disease, even if it is bad news• more details about their test results and prognosis• appropriate timing of information and tailored to the patients' needs

Project overview

Developing SMICS' supportive care agenda

In 2008-09 SMICS undertook a consultation project to map current supportive care services and to develop supportive care priorities across southern Melbourne's cancer services. Seven inter-related priorities were agreed:

1. increasing the profile of supportive care
2. improving access to a skilled supportive care workshop
3. screening for supportive care needs
4. patient communication and access to information
5. access to emotional support, counselling, psychology and mental health services
6. access to palliative care resources
7. continuity and integration of care

Developing the project aim

The consultation process identified the development and implementation of supportive care screening as a priority for Alfred Health, amongst other areas.

Alfred Health: identified priorities

- within organisational checklist
 - Liverpool end of life care pathway specifically identified as priority (along with earlier referral to palliative care and palliative care participating in MDT meetings)
 - strengthening relationships with GPs
- In earlier consultation discussion
 - increasing workforce capacity
 - strengthening understanding of supportive care across whole MDT team, integrating into MDT case planning, strengthening referral into supportive care / psych services
 - **strengthening screening**
 - strengthening access to information (standard packs etc.)

After endorsement through the SMICS Governance Committee, the proposal was developed to pilot a supportive care screening tool in the Haematology Oncology Clinic at Alfred Hospital.

Project methodology

The primary **purpose** of the project was to pilot an agreed supportive care screening tool to identify the needs of all new patients attending the Haematology Oncology Clinic (HOC) at Alfred Hospital.

The specific project **deliverables** included:

- designing and testing an agreed supportive care screening tool
- confirming referral pathways for identified needs (to allied health areas)
- education of staff
- evaluation and data analysis
- a final report and recommendations

The project **scope** included the following:

- drawing on the development of existing supportive care screening tools
- establishing a Working Group to guide and support the pilot
- screening newly diagnosed Medical Oncology patients attending their first chemotherapy appointment
- have provisions for referral to allied health services as indicated through the completion of the tool

The project scope *excluded*:

- the ongoing funding of supportive care services
- screening of patients already receiving chemotherapy treatment
- patients with a haematological cancer diagnosis (during the pilot there were 2 patients with a haematological malignancy that were treated by the Medical Oncology team who were included)

Project advisory mechanisms

A Working Group was established and chaired by the Co-Director, Medical Specialties at Alfred Health (up to February 2010). Membership included the following Alfred Health staff:

- Director, Allied Health
- Nurse Manager, Haematology Oncology Clinic
- Nurse Manager, 7East Ward
- Cancer Support Nurses
- Dietetics
- Social Work
- Psychology
- Physiotherapy
- Occupational Therapy
- Speech Pathology
- Bone Marrow Transplant Coordinator
- Haematology Care Coordinator

Key project activities

Planning phase included the design of the screening tool (see page 9) and endorsement of the project plan; ethics approval was received through Alfred Health's Human Research Ethics Committee.

Referral pathways were to be endorsed by the allied health staff and a decision tree for how to address the needs identified on the screening tool. This process also supported the use of existing information and resources.

Staff education included 2 sessions, as part of existing HOC staff meetings. The sessions allowed a brief overview of supportive care, the aim of the pilot and expected processes for nurses and allied health staff.

Pilot commencement included ready access to screening tools and patient consent forms in the HOC, for staff to provide to patients at their first appointment. Nurses would discuss the screening tool with the patients and consider if referrals were required (based on the agreed referral pathways – above). The screening tool was placed in a tray for data collection (SMICS Cancer Service Improvement Coordinator) and an e-referral was sent to allied health areas (if referral required).

Post-pilot evaluation: a survey was sent to the patients (outlined on patient consent form); seeking their feedback about the screening tool itself (usefulness / format) and the screening process (time with the nurse / referrals). A one-off staff forum was held with HOC staff to gauge their feelings and experiences about the tool and the process. Data collected from the screening tools was also analysed.

A **final report** outlining the findings and suggested future activities was then completed.

Development of the supportive care screening tool

Within the last couple of years, health services and ICS' across Victoria have been in the process of developing or piloting existing supportive care screening tools (Table 3).

Table 3. Existing screening tools

Screening tool	Brief description
Brief Symptom Inventory (USA)	A patient-reported form: nine dimensions (53 items) on a five point rating scale. Has to be purchased. Is not cancer specific, and doesn't address all supportive care domains (information, spiritual, physical).
Distress Thermometer and Problem Checklist (USA)	A free tool with five dimensions (35 dimensions) and an 11 point scale (thermometer) for 'how distressed' a patient has been over the previous week. Created specifically for cancer population, but transferable across services.
Hospital Anxiety and Depression Scale (USA)	A patient-reported form: 14 items measuring anxiety and depression separately. Doesn't address all supportive care domains (information, spiritual, physical).
Kessler Psychological Distress Scale (K10) (USA)	A quick and easy form: 10 questions about negative emotional states experienced during the 4 weeks prior to the assessment. Doesn't address all supportive care domains.
Supportive Care Needs Survey (AUS)	<i>Centre for Health Research and Psycho-oncology (CHeRP)</i> Is comprehensive and useful in research and evaluation projects. Is difficult to review quickly and the time taken to complete form may be barriers in clinical setting.
Supportive Needs Screening Tool (AUS)	<i>Peter MacCallum Cancer Centre (PMCC)</i> Is comprehensive and useful in research and evaluation projects. Time taken to complete is a barrier and may not be relevant for some cancer groups.

The Working Group considered these tools with the aim of screening for supportive care needs. In addition they considered:

- identifying current levels of distress and need – the existing screening tools address this
- identifying risk factors – evidence suggests that identifying risk factors is as important (NBCC and NCCI 2003) as screening for current levels of distress and need
- identifying other allied health-specific risk factors

Therefore the following screening tool elements were proposed (see Attachment 1):

- **Distress Thermometer and Problem Checklist** (validated)
- questions addressing three **risk factors**:
 - had the patient previously had treatment for emotional problems? (yes or no)
 - how supported did the patient feel by family and friends? (11-point scale)
 - how much help did the patient need for their concerns? (11-point scale)
- **Malnutrition Screening Tool** (MST) (validated)
 - have you lost weight without trying?
 - have you been eating poorly because of a decreased appetite?
 - do you follow a special diet at home (e.g. for diabetes?)
- **physiotherapy** questions
 - have you had any falls?
 - have you noticed any changes in your balance whilst walking?
 - have you used a gait aid? (how long / what was used)
 - have you felt a sense of 'heaviness' or noticed any swelling in your arms or legs?
 - would you like further advice regarding exercise or physical activity?
- **speech pathology** questions
 - are you having any difficulty swallowing?
 - have you recently started to cough or choke when you eat and drink?
 - are you having any new difficulties understanding what people are saying to you (in your first language)?
 - have you had any recent difficulty speaking or communicating?
- **occupational therapy** questions
 - have you experienced difficulties in you're ability to carry out everyday activities (e.g. showering, preparing meals, getting in and out of bed)?
 - have you experienced fatigue, anxiety and/or pain which has impacted on your everyday activities such as brushing teeth, eating, dressing or working?
 - have you had difficulty with remembering things, concentrating or felt confused or disorientated?

Each of the allied health-specific questions were weighted (given a score), depending on anticipated level of need. The MST is the only allied health section where the weighting of each question is validated. For physiotherapy, speech pathology and occupational therapy, the scores were agreed by the Working Group (see Attachment 1).

Findings

This section is divided into the following sections:

- findings from the screening tool data collection
 - demographics
 - Distress Thermometer score
 - Problem Checklist
 - allied health-specific questions
 - risk factor questions
- patient survey responses
- HOC staff forum – feedback

The NCCN Guidelines of Distress Management⁴ recommend a score of 4 or above as being representative of patient distress. The pilot reflected this guideline in the referral flowchart and the data has been analysed in a similar way. The data is broken into three sub-groups:

- Distress score of 3 or below
- Distress score of 4 or above
- Distress score – incomplete (-)

The allied health-specific questions were analysed according to the agreed criteria for each set of questions, in addition to the above sub-groups.

Screening tool data

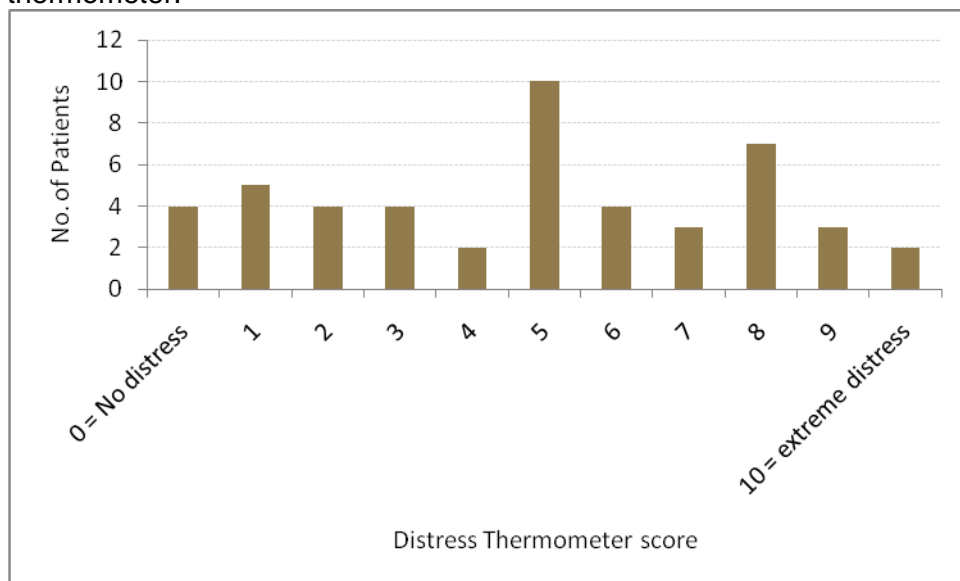
The sample of n=50 was collected during the pilot. There was no demographic data provided for one of these 50 patients. A full analysis of the data is in Attachment 3.

Table 4: Demographics

Sex	n (%)	Cancer Stream	n (%)
Male	26 (52%)	Upper GI	14 (28%)
Female	23 (46%)	Breast	9 (18%)
Unknown	1 (2%)	Colorectal	8 (16%)
<i>Total</i>	50	Lung	7 (14%)
Age	n (%)	Haematology	2 (4%)
Range	25-80	Head and Neck	5 (10%)
Median	60	Skin	3 (6%)
Mean	60.6	Genito-urinary	1 (2 %)
SD±	12.4	Unknown	1 (2%)
Location	n (%)		
Metropolitan	42 (84%)		
Regional	7 (14%)		

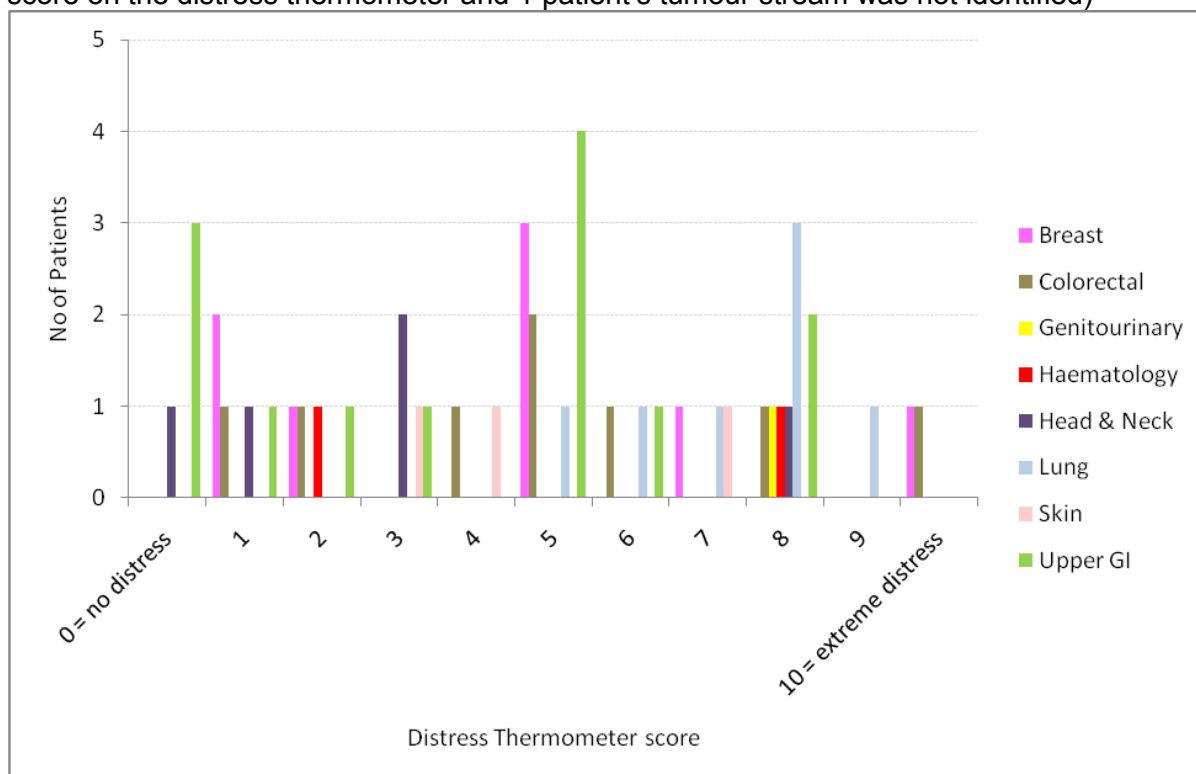
There was almost equal representation between males and females in the pilot. The average age of the patients was 60. Almost a third (28%) of patients had an Upper GI cancer diagnosis, followed by a Breast (18%) and Colorectal (16%) cancer diagnosis.

Graph 1: Distress Thermometer (n=48) 2 patients did not record a score on distress thermometer.

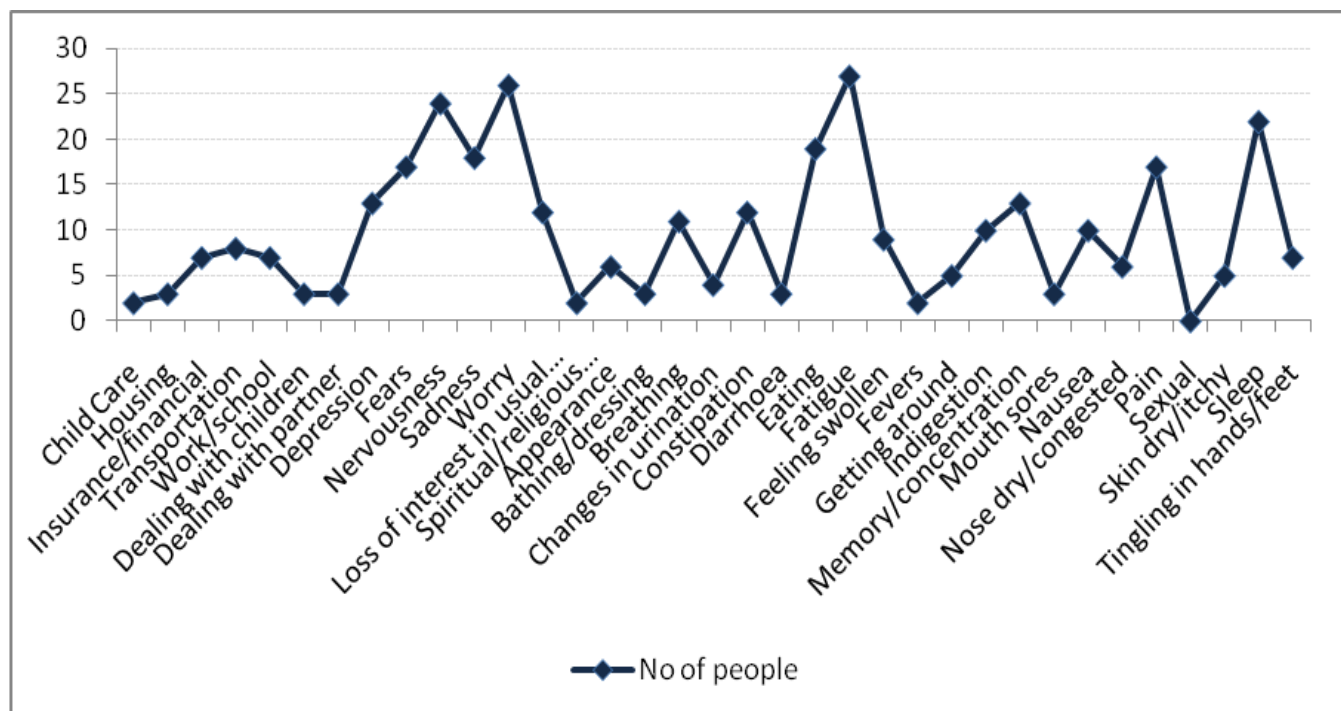


Scores of 5 and 8 out of 10 were reported most often (n=10 and n=7 respectively). The average distress thermometer score was 4.7 over the total sample (n=48). Two patients did not record a score on distress thermometer. 31 out of 48 patients (64.6%) reported having their distress as being 4 or above over the past week.

Graph 2: Distress Thermometer by Tumour Stream (n= 47) (2 patients did not record a score on the distress thermometer and 1 patient's tumour stream was not identified)



Graph3: Problem Checklist



The most significant problem identified by patients was fatigue. This was followed by worry, nervousness and sleep. All of the emotional problems scored highly (over 25% of the patients). A full analysis of the data is provided in Attachment 3.

Physiotherapy questions

The physiotherapy questions were:

- have you had any falls?
- have you noticed any changes in your balance whilst walking?
- have you used a gait aid? (how long/what was used)
- have you felt a sense of 'heaviness' or noticed any swelling in your arms or legs?
- would you like further advice regarding exercise or physical activity?

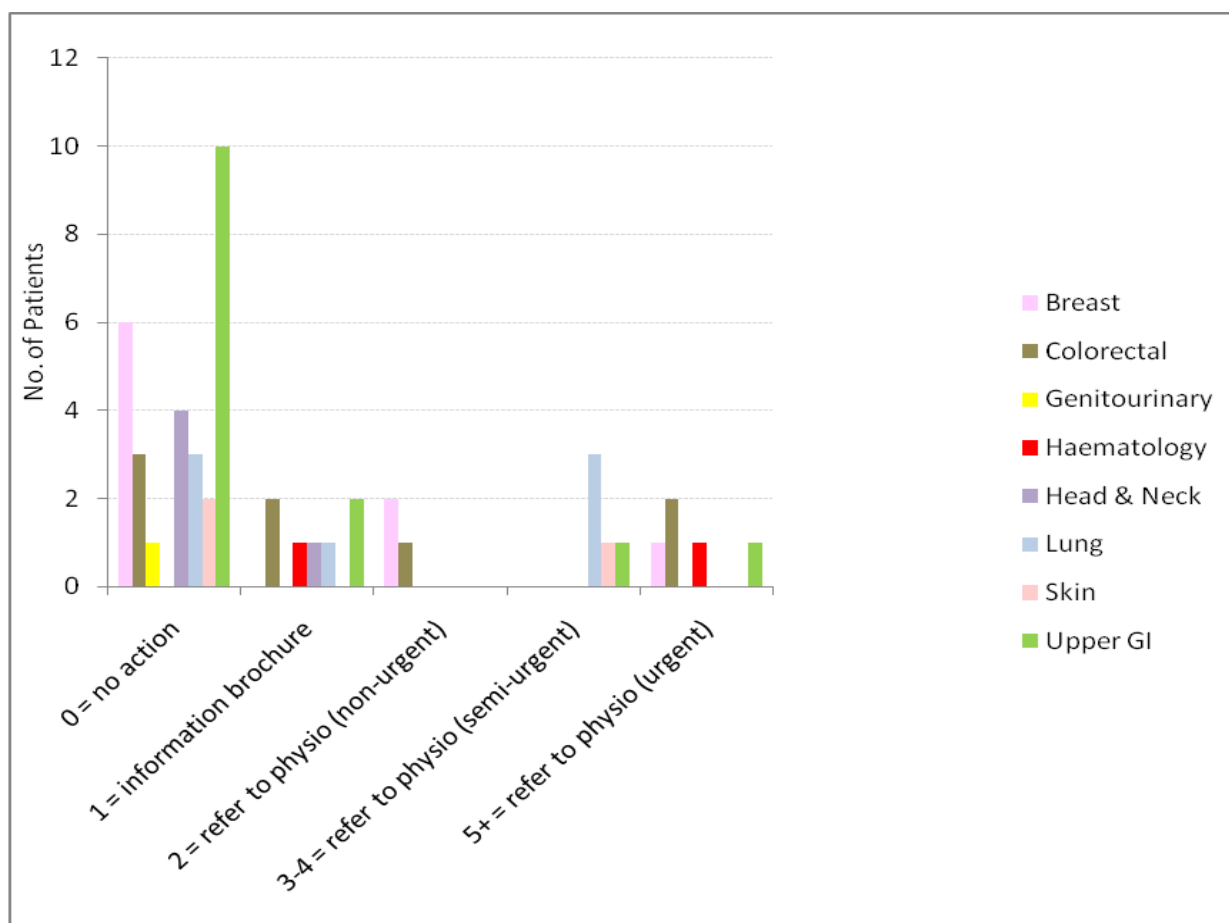
The questions were weighted (see Attachment 1) and the scores were totalled and categorised as follows:

- 0: no action
- 1: information brochure
- 2: refer to physiotherapy (non-urgent)
- 3-4: refer to physiotherapy (semi-urgent)
- 5+: refer to physiotherapy (urgent)

Table 5: Physiotherapy needs by total score

	dt≤3		dt≥4		dt(-)		Total (n=50)	
	n	%	n	%	n	%	n	%
0: no action	12	24	15	30	2	4	29	58
1: information brochure	1	2	6	10			7	14
2: refer to physiotherapy (non-urgent)	1	2	1	2			2	4
3-4: refer to physiotherapy (semi-urgent)	1	2	5	10			6	12
5+: refer to physiotherapy (urgent)	2	4	4	8			6	12

Graph 4: Physiotherapy needs by tumour stream (n=49 as 1 patient's tumour stream could not be identified)



58% (n=29) of patients did not identify any physiotherapy needs in the pilot. 28% (n=14) of patients had total scores over 2, which meant a referral to physiotherapy should be considered. Ten of these fourteen patients scored themselves as 4 or above on the Distress Thermometer. Lung, Colorectal and Breast had slightly more patients identifying physiotherapy needs than the other cancer streams.

Malnutrition Screening Tool questions (Dietetics)

The dietetic questions were:

- have you lost weight without trying?
- have you been eating poorly because of a decreased appetite?
- do you follow a special diet at home (e.g. for diabetes?)

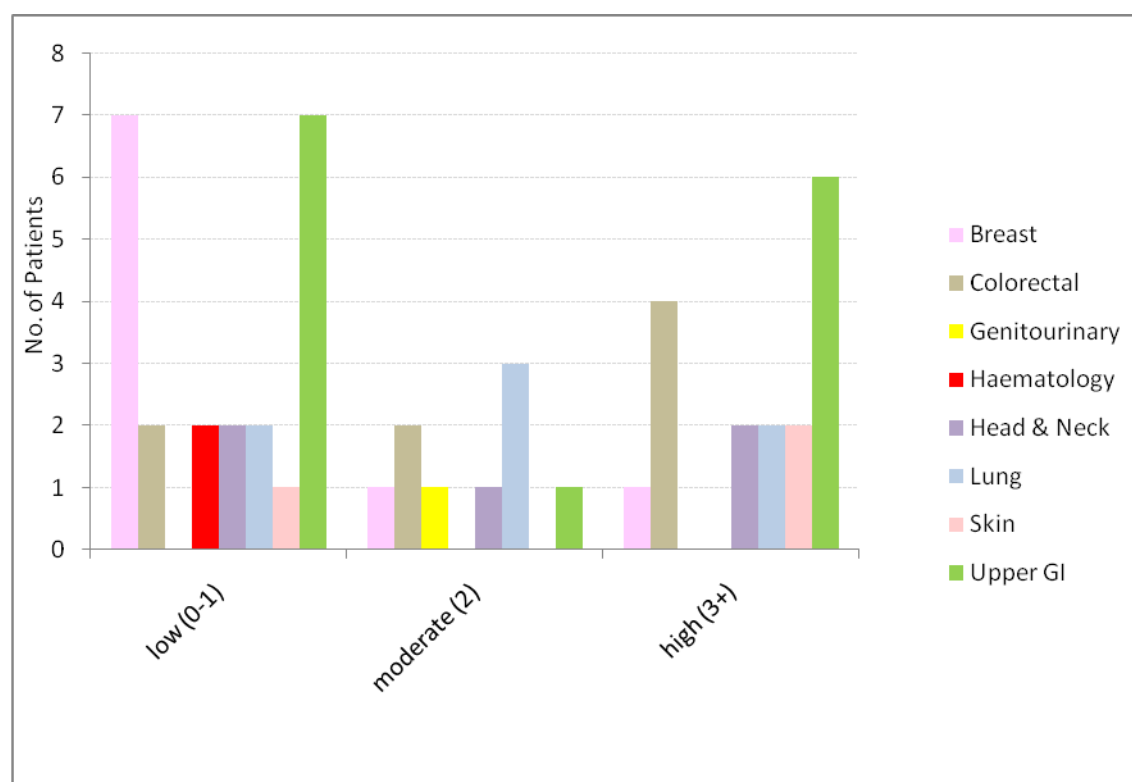
The questions were weighted and the scores were totalled and categorised as follows:

- 0 – 1 : low malnutrition risk
- 2 : moderate risk
- 3 + : high malnutrition risk

Table 6: Malnutrition needs by total score

	dt ≤ 3		dt ≥ 4		dt (-)		Total (n=50)	
	n	%	n	%	n	%	n	%
low (0-1)	5	10	17	34	2	4	24	48
moderate (2)	1	2	8	16	-	-	9	18
high (3+)	9	18	8	16	-	-	17	34

Graph 5: Malnutrition needs by Tumour Stream (n = 49)



In total, over 50% (n=26) of patients had either moderate or high malnutrition risk. Sixteen (16) of these patients had a distress score of 4 or higher. Skin (2 out of 3 patients = 66%), Colorectal (50%), Head & Neck (40%) and Upper GI (43%) had the greatest proportion of patients with a high malnutrition risk identified.

Speech Pathology questions

The speech pathology questions were:

- Are you having any difficulty swallowing?
- Have you recently started to cough or choke when you eat and drink?
- Are you having any new difficulties understanding what people are saying to you (in your first language)?
- Have you had any recent difficulty speaking or communicating?

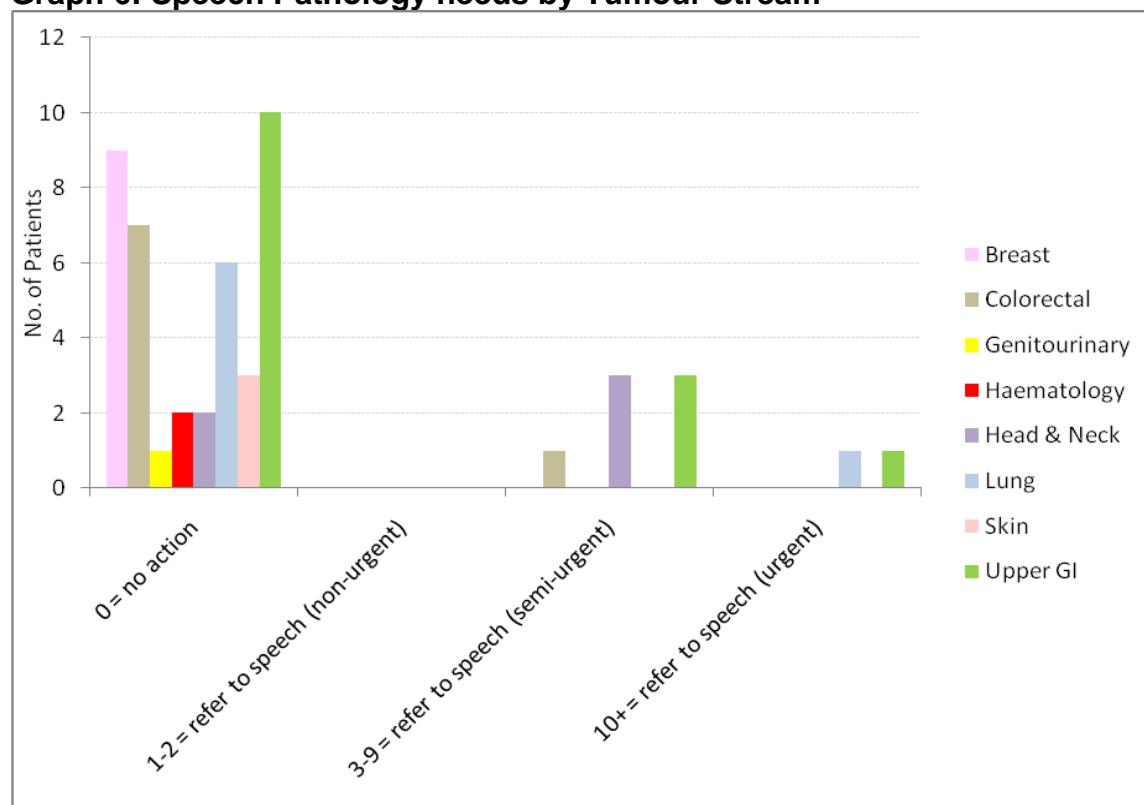
The questions were weighted and the scores were totalled and categorised as follows:

- 0 : no action
- 1-2 : refer to speech pathology (non-urgent)
- 3-9 : refer to speech pathology (semi-urgent)
- 10+ : refer to speech pathology (urgent)

Table 7 : Speech Pathology needs by total score

	dt ≤ 3		dt ≥ 4		dt (-)		Total (n=50)	
	n	%	n	%	n	%	n	%
0 : no action	13	26	26	52	2	4	41	82
1-2 : refer to speech pathology (non-urgent)	-	-	-	-	-	-	-	-
3-9 : refer to speech pathology (semi-urgent)	4	8	3	6	-	-	7	14
10+ : refer to speech pathology (urgent)	-	-	2	4	-	-	2	4

Graph 6: Speech Pathology needs by Tumour Stream



More than 80% of patients did not require speech pathology intervention at their first appointment, based on the screening tool. Of those who did score more than 3 (n=9), five had a distress score of 4 or above. The predominant tumour stream was Head & Neck with 3 out of 5 patients requiring a 'semi-urgent' referral. Lung and Upper GI both had one patient each who scored over 10 requiring urgent referrals.

Occupational Therapy questions

The Occupational Therapy (OT) questions were:

- have you experienced difficulties in your ability to carry out everyday activities (e.g. showering, preparing meals, getting in and out of bed)?
- have you experienced fatigue, anxiety and/or pain which has impacted on your everyday activities such as brushing teeth, eating, dressing or working?
- have you had difficulty with remembering things, concentrating or felt confused or disorientated?

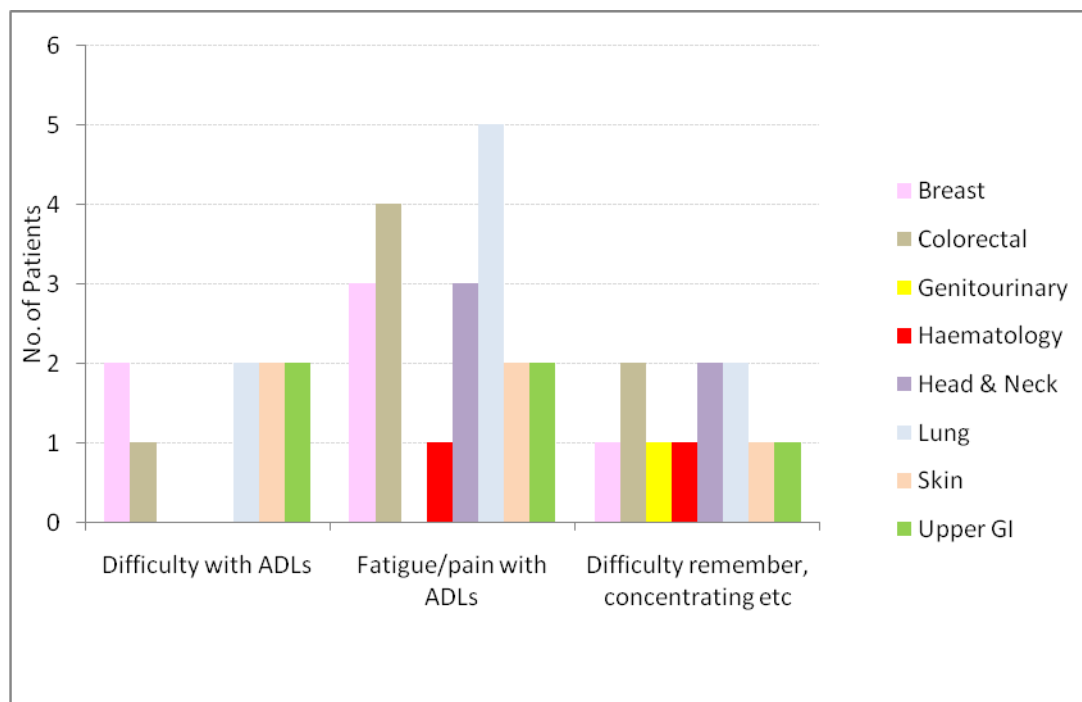
The questions were scored individually (no = 0; yes = 1) and were actioned as follows

- Question 1 – difficulty with Activities of Daily Living (ADLs): if yes, consider referral to OT
- Question 2 – fatigue, anxiety and/or pain associated with ADLs: if yes, consider brochure on fatigue management and/or referral to OT
- Question 3 – memory and/or concentration difficulties: if yes, consider referral to OT.

Table 8: Occupational Therapy needs by Score

	dt ≤ 3		dt ≥ 4		dt (-)		Total	
	n	%	n	%	n	%	n	%
Question 1: Difficulties with ADLs (n=50)	2	4	7	14	-	-	9	18
Question 2: Fatigue/pain with ADLs (n=49)	7	14	13	26	-	-	20	41
Question 3: Memory/concentration difficulties (n=50)	5	10	6	12	-	-	11	22

Graph 7: Occupational Therapy needs by Tumour Stream



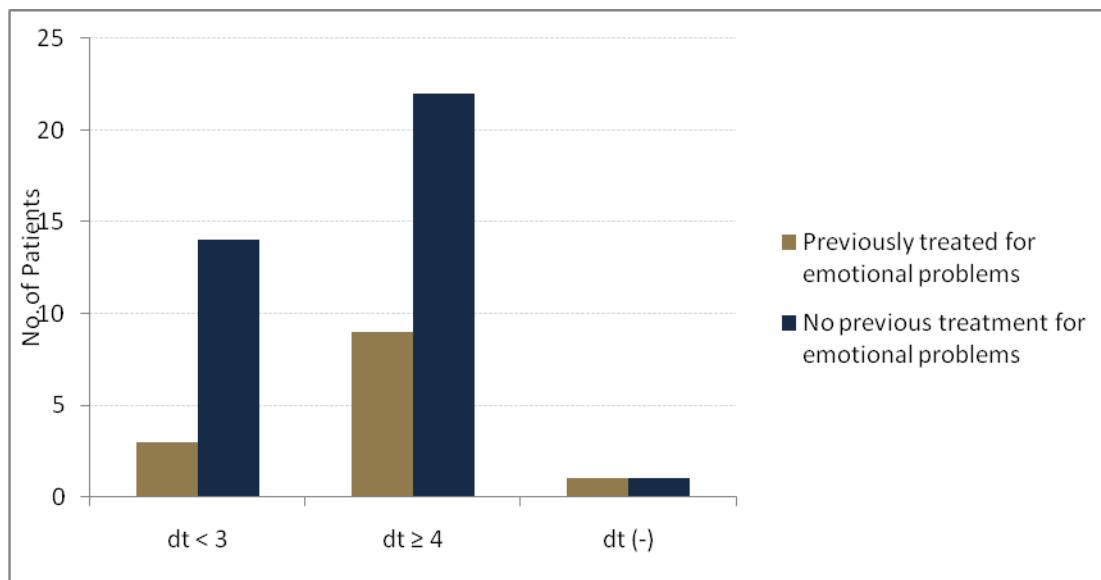
In line with the findings of the Problem Checklist (see page 29), fatigue and pain were most often reported in the occupational therapy questions. Twenty (40%) reported having difficulties and this was across both sub-groups (distress of 3 or less; 4 or higher). This was represented most often for Lung patients (n=5), followed by Colorectal (n=4).

Risk Factor questions

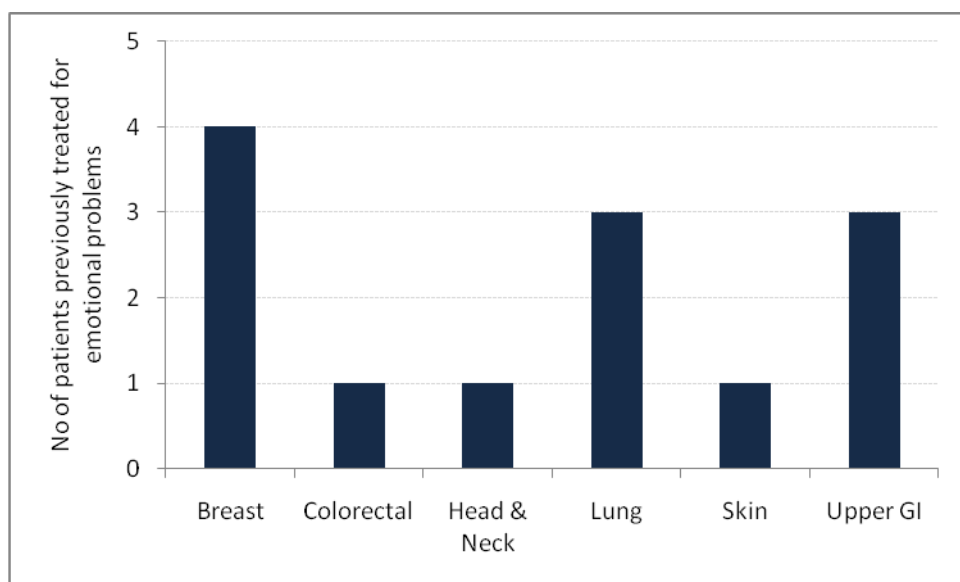
The risk factor questions were:

- have you previously had treatment for emotional problems?
- how supported do you feel by family and friends?
- how much help do you need for these concerns?

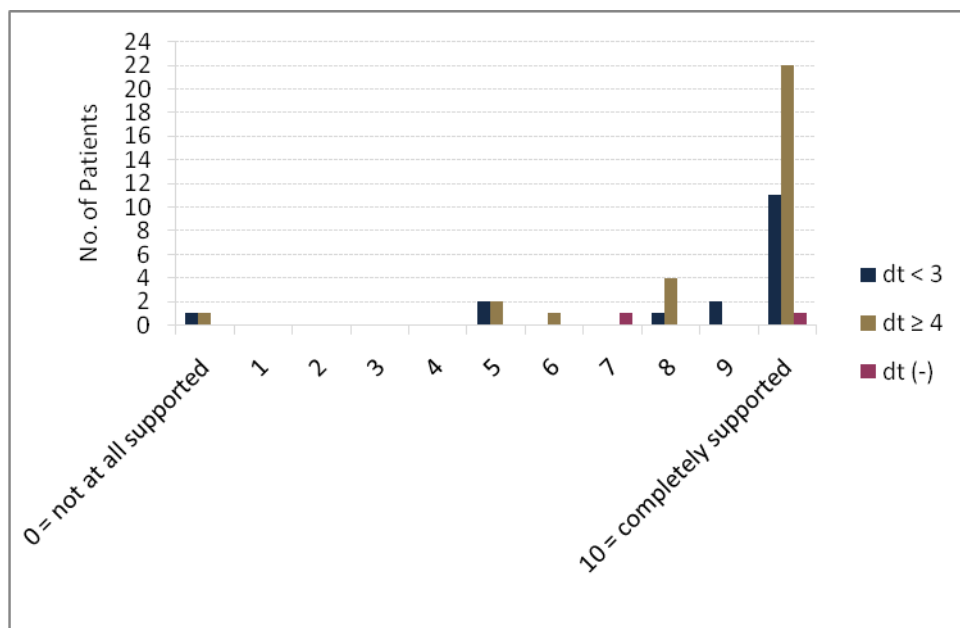
Graph 8: Patients who previously received treatment for emotional problems



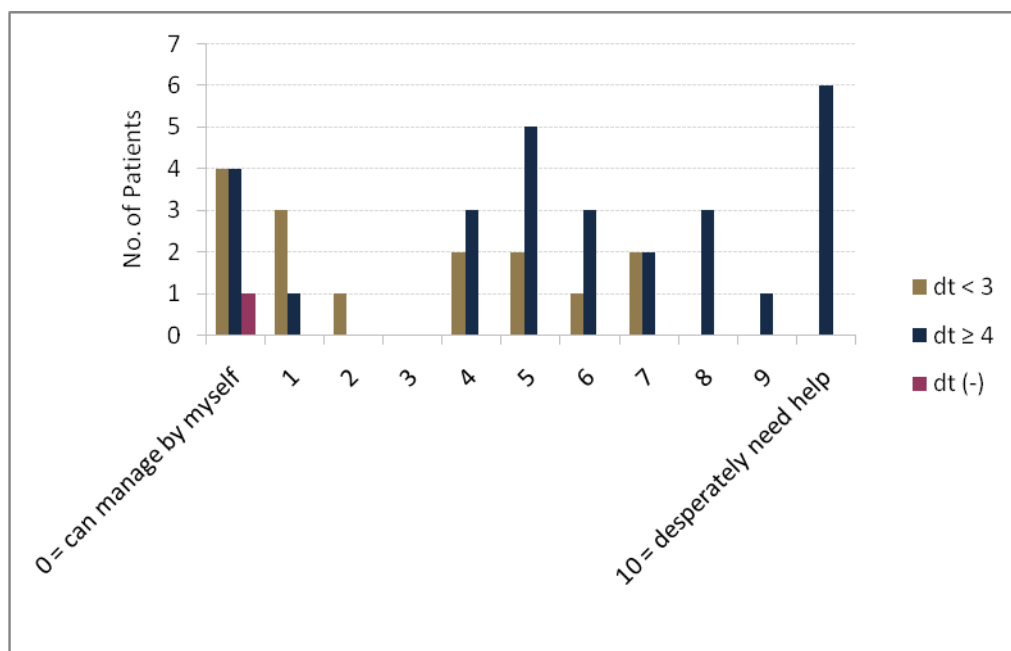
Graph 9: Patients who previously received treatment for emotional problems by tumour stream (n = 13)



Graph 10: How supported did patients feel by their family and friends?



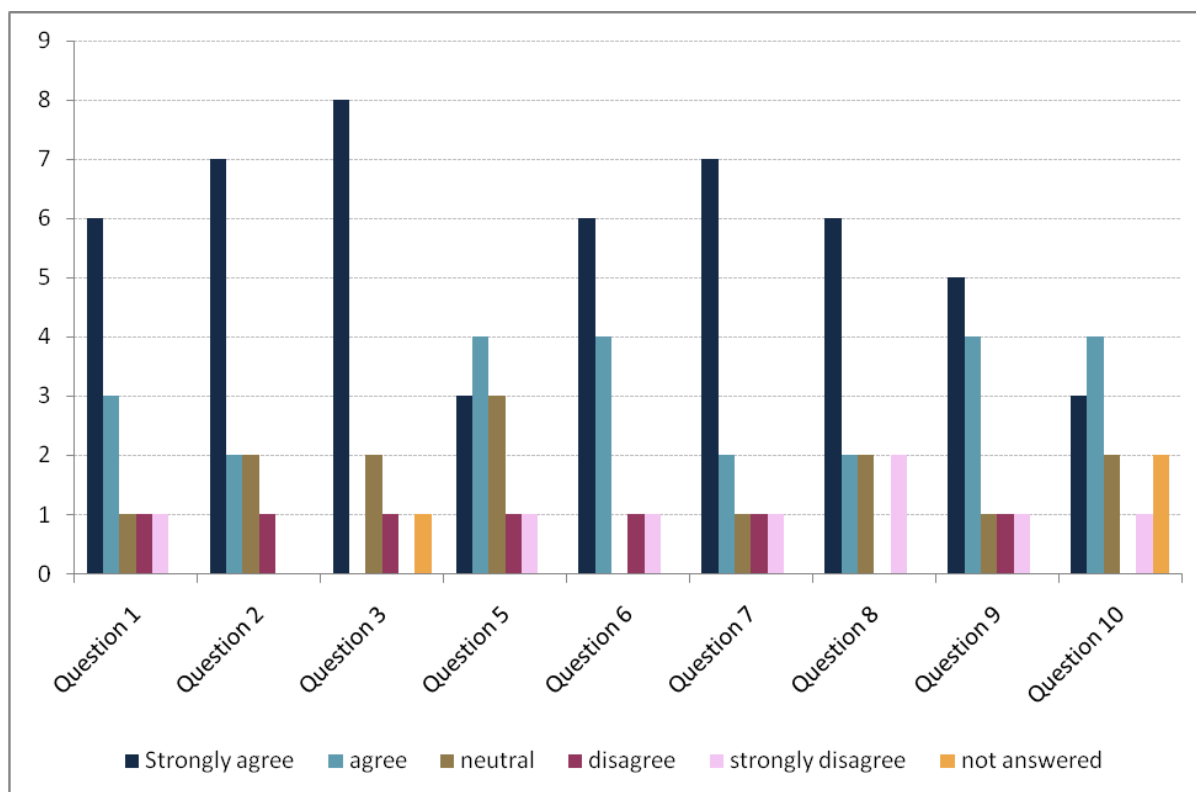
Graph 11: Level of support required by patients in addressing their needs



Patient Survey

A survey was sent to the participating patients at the end of the pilot (Attachment 2), to seek their feedback about the format, language and usefulness of the screening tool. A total of 12 surveys were returned (24.5% response rate).

Graph 10: Patient survey responses



From the 12 patients (24.5%) who responded, a level of acceptance for the screening tool and process was identified.

Questions 1 and 2 asked whether the patients' were able to *understand and read* all of the questions. Nine of the twelve respondents (75%) strongly agreed or agreed that this was the case.

There was strong agreement (66.7%) with respect to respondent's *feeling comfortable* about completing the screening tool (Question 3), however only just over half (58.3%) thought that it *helped them think about their needs other than just the treatment* (Question 5).

Question 6 asked if patients felt the time spent with the nurses discussing the treatment and screening tool was useful. All but two agreed with this statement and 9 respondents felt that *they could ask questions* as well (Question 7).

Sixty seven percent (n=9) of responses found the room appropriate for discussions with the nurses (Question 8), however 2 respondents disagreed that the information they were provided with was provided with was appropriate (Question 9).

Question 10 asked whether patient's found the referrals appropriate, with seven (7) agreeing this was the case. It wasn't applicable in two (2) cases and one respondent strongly disagreed.

NB. Question 4 was removed from the analysis as it referred to a process which was changed during the pilot.

HOC staff feedback

At the end of the pilot, HOC nursing staff were asked for their feedback about the screening tool, the screening and referral processes and their suggestions. Ten staff participated in a 45-minute discussion. The table below summarises the themes discussed by the group.

Initial staff education	This was good for an initial overview of supportive care. The group suggested re-confirming the education at the mid-point of the pilot. This would also allow feedback about review how the pilot was tracking.
Screening tool	<p>Staff considered the tool quite 'big' and 'busy'. That it required a lot of patient commitment to complete all the sections. Some staff had experienced the language not being appropriate for culturally and linguistically diverse groups and varying education levels.</p> <p>Page one The staff supported the elements on the first page, noting the above comment regarding usefulness for people with languages other than English.</p> <p>Page two The staff found this too clinical and that patients' felt 'overawed'. There were occasions when sections were left blank, and when scores weren't filled in, with several staff stating that it 'wasn't clear enough'.</p>
Process	<p>Staff did find that having the screening tool completed at the patients' first HOC appointment was a burden – for patients and staff. This is because learning about their chemotherapy treatment is a priority. Some staff also found that patients' developed an expectation that each of the allied health services 'was available' to them, without a need being identified.</p> <p>The staff suggested handing out the screening tools when patients came to see the consultants. The tool could be used as a prompt, but more importantly, it still happens prior to the patients' first HOC appointment.</p>
Process (cont'd)	<p>This is also located in the non-clinical section of the service.</p> <p>There was discussion about how to determine when re-screening should also occur.</p>
Information provision	<p>The staff did not find that the screening tool had any impact on information provision. The detail required for the existing nursing assessment tool ensured many similar things were covered.</p> <p>Once again, managing expectations of some patients' was raised. Clear communication around this issue was agreed.</p>
Referrals	The staff acknowledged that the screening tool provides data which can identify and support the demand for supportive care services. The group considered reports being raised through the e-Referral system to monitor this. Some individuals noted they still use the phone for referrals as it is quicker when no computers are available.
Limitations experienced by staff	<p>The group acknowledged several key issues which impacted on the pilot:</p> <ul style="list-style-type: none">• a significant increase in the number of patients attending the HOC• no administrative support (ward clerks) to assist

Discussion

Evidence suggests that patients with cancer can experience significant distress from the time of their diagnosis through to treatment, follow up care and palliation. An increased body of evidence demonstrates the positive benefits associated with the recognition of needs and subsequent actions taken, to help the patient and their family and carers as they move through the health system.

This pilot examined the use of an adapted screening tool, based around the NCCN's Distress Thermometer and Problem Checklist. It also included the Malnutrition Screening Tool (MST), allied health-specific questions and questions relating to the following risk factors:

- previous treatment for emotional problems
- support by family and friends
- how much help patients thought they needed

Developing the screening tool

During the pilot, SMICS was communicating with other ICS' about their screening activities. It was recognised that the approach taken for this pilot (i.e. using the Distress Thermometer and Problem Checklist in addition to questions from allied health and risk factors) was different to other similar projects.

Rationale

This project aimed to consider the services, priorities and challenges faced by the staff in the HOC at Alfred Hospital. To do this, the Working Group recognised that the Distress Thermometer and Problem Checklist on their own would not adequately address the needs of both the patient population and the HOC staff. The decision to design a combined screening tool allowed for two things:

- a more comprehensive view of the patient (social supports, emotional background and level of self-sufficiency)
- additional allied health information where referrals were required

Screening tool findings

From November 2009 until May 2010, 50 patients were screened for their supportive care needs in the Haematology Oncology Clinic at the Alfred Hospital (Alfred Health).

Distress Thermometer and Problem Checklist

In this pilot, 64.6% of patients (n=31 out of 48 patients) were significantly distressed (distress score of 4 or above). The average patient scored 5.

Multiple supportive care needs were experienced by patients, although the most predominant problems included **fear**, **nervousness** and **worry**, and **loss of interest in usual activities**. **Fatigue**, **sleep** and **pain** were most significant in the physical problem domain. This is similar across the sub-groups (distress score: 3 or less; 4 or more; incomplete). These findings support existing evidence that fatigue, anxiety and distress are often exhibited in 15-23% of patients (NBCC and NCCI 2003).

Physiotherapy questions

The pilot demonstrated that for a majority of patients (58%), falls, swelling, balance and other related physiotherapy issues were not relevant at their first appointment. Of the fourteen patients that did report these issues, ten had distress scores higher than 4. They were mostly diagnosed with lung cancer (n=3), colorectal cancer (n=3) or breast cancer (n=3).

Malnutrition Screening Tool (MST)

The screening tool included three standard questions related to risk of malnutrition. The data from this pilot suggests that over 50% of patients were at either high or moderate risk of malnutrition at their initial chemotherapy appointment. This was reflected with the Problem Checklist findings, with eating (41.3%), constipation (26.1%) and indigestion (21.7%) all rating highly. This was predominantly the case for patients who scored 4 or above on the Distress Thermometer.

Speech pathology questions

The specialist issues associated with speech pathology were considered by the Working Group to not often be identified at a patient's initial appointment in the HOC. The results of the pilot illustrated that for over 80% of patients, this hypothesis was correct. When these issues were identified, it was primarily for lung and upper GI patients. This was an unexpected outcome, as speech pathology is attributed most often with head and neck cancer patients. In this pilot, only 1 of 5 head and neck patients were identified as requiring a referral (semi-urgent).

Occupational Therapy questions

The OT questions related to difficulties with daily living, fatigue and anxiety, and memory or concentration issues. The results of the pilot indicated that after dietetics, OT was second in terms of identified needs and by extension, demand for referrals.

For patients who scored 3 or below on the distress thermometer, 35.3% had identified fatigue and/or anxiety – a finding not replicated within the other allied health-specific sections. For patients who scored 4 or above on the distress thermometer, over 46% reported fatigue and/or anxiety as a problem. These findings were strongly supported by the results from the Problem Checklist, which illustrated fatigue was the most reported issue (58.7%) on the screening tool. This was represented most often for Lung patients (n=5), followed by Colorectal (n=4).

Patient survey findings

Surveys were sent out to the 49 patients who consented to participating in the pilot (there was no demographic data for one patient). Of these, 12 surveys were returned (24.5% response rate).

Nearly all respondents agreed or strongly agreed that the screening tool was understandable and the words could be understood. Sixty seven per cent (67%) strongly agreed that they *felt comfortable* in answering the questions. This finding was encouraging, with respect to supportive care screening in general, as some HOC staff had concerns that patients may not like to answer questions they viewed as sensitive.

Of note, only half of respondents felt that the screening tool made them consider issues other than just their treatment. This finding suggests that some patients may already have sourced information about their diagnosis, or had actively asked questions from health professionals. The survey also asked whether patients felt they had appropriate time with the HOC nurses and could ask questions about the screening tool. Over 75% agreed with these statements (n=9).

HOC staff feedback

The support from HOC staff was positive throughout the pilot. Feedback indicated that the level of education about supportive care, and about the screening tool itself was appropriate – given time constraints and demand for nursing resources, any greater amount of time (over 60 minutes) was not feasible.

Staff suggested having a similar event mid-way through the pilot, to remind existing staff of the purpose and to introduce new staff to the pilot and changes.

Although some staff commented that the burden to complete all sections of the tool was significant for patients, the patient survey does not indicate this. Ninety per cent (90%) of patients felt comfortable in answering the questions and found the time with staff, and opportunity to ask questions quite useful.

Valid suggestions were made about the process of screening new patients. At a patient's first chemotherapy appointment, they are provided with a significant amount of information, asked a multitude of questions and are subject to several tests before then receiving treatment. This appointment was not considered the most appropriate for the screening tool completion. Staff commented that at a patient's initial appointment, where patients meet with the consultants, would be better suited: it is in the non-clinical area of the service (less upsetting), there is time for the patients to not only meet with the consultants, but they also have one on one meetings with a member of the nursing staff, and it ensures that needs can be identified *prior* to the treatment being delivered on the first occasion.

These comments also reflect a recent change in the orientation of new patients within HOC.

Project limitations

The project was intended as a small pilot study to assess the usefulness and feasibility of using a supportive care screening tool within the HOC setting. Prior to the commencement, the Working Group agreed that screening 100 new patients should be feasible within a 10-12 week period.

After nearly 20 weeks, the pilot was ceased, with only 50 patients having been screened. As is similar with other projects in a clinical setting, there are variables beyond the control of the Working Group. The following were identified as contributing to this low screening rate:

- the HOC experienced a significant increase in patient numbers during the time of the pilot
- at present, the HOC does not have an administrative role to support clinical staff in undertaking basic coordination of tasks, such as copying the screening tool, keeping them readily available for when new patients arrive etc – this was seen as a significant barrier by the Nurse Manager and HOC staff
- continued promotion and support from SMICS staff, i.e. visiting the HOC on a regular basis to check for completed tools and discussing issues with staff
- confusion surrounding whether referrals could actually be made to allied health, if identified on the screening tool. As a result screening tools were not being undertaken for some new patients. Although feedback about the initial education was positive, this suggests that more emphasis on promoting referrals to allied health was required – and that this had been endorsed by the allied health representatives on the Working Group.

Recommendations

The project has demonstrated the usefulness of a supportive care screening tool for identifying referral needs in the HOC setting. The findings of the pilot reflected existing evidence about supportive care and the role that screening has in identifying patient needs from an early stage. It is recommended that:

- the findings of this pilot be considered in deliberations of the wider implementation of supportive care screening at Alfred Health, and across the southern Melbourne region
- a documented process be established within the Haematology Oncology Clinic for the screening of new patients, and the subsequent referrals required to address their needs
- the screening tool design be formalised, for inclusion in the Alfred Health medical record (and scanned medical record).
- active engagement with allied health and cancer support nurses continues, to consider service planning and information provision for patients with a new diagnosis of cancer
- consideration also be given to the translation of the agreed screening tool into several of the more predominant languages at each health service, i.e. Greek, Italian, Vietnamese
- consideration also be given to evaluating any agreed supportive care screening tool in 12-18 months time, to assess the feasibility of the tool across health services and across southern Melbourne.

Attachment 1. Final version of screening tool for pilot



The following questions provide an opportunity to work out the kinds of support that may be most helpful for you and your family during your treatment. You can ask a family member or carer to help.

Please complete both sides of this form and hand it to your nurse at your first appointment.

AlfredHealth

NCCN® Practice Guidelines in Oncology – v.1.2008		Distress Management		Screening date:																																																																																																																																				
Instructions: 1. Please circle the number (0-10) that best describes how much distress you have been experiencing in the past week including today.																																																																																																																																								
		2. Please indicate if any of the following has been a problem for you in the past week including today. Be sure to tick YES or NO for each.		3. Have you previously had treatment for emotional problems: NO YES (e.g. anxiety/depression)																																																																																																																																				
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ONCOLOGY SUPPORTIVE CARE SCREENING TOOL MR (pilot project) #

ONCOLOGY SUPPORTIVE CARE SCREENING TOOL MR (pilot project) #

5. PHYSIOTHERAPY In the last three months (please CIRCLE): Have you had any falls? No ⁰ Yes ⁵ Have you noticed any changes in your balance whilst walking? No ⁰ Yes ³ Have you used a gait aid? No ⁰ Yes ¹ If yes, how long have you been using it? 0-3 months ² 4-6 months ¹ >6 months ⁵ If yes, what aid do you use? Walking stick Walking frame Wheelchair Other (please specify) Have you felt a sense of 'heaviness' or noticed any swelling in your arms or legs? No ⁰ Yes ² Would you like any further advice regarding exercise or physical activity? No ⁰ Yes ¹ TOTAL SCORE (staff use only)		7. SPEECH PATHOLOGY In the last week including today: Are you having any difficulty swallowing? No ⁰ Yes ³ If yes, is this related to pain when eating and drinking? No ⁰ Yes ¹ If yes, is this causing you distress? No ⁰ Yes ¹ If yes, is this limiting the amount and type of food and drink you can manage? No ⁰ Yes ¹ Have you recently started to cough or choke when you eat and drink? No ⁰ Yes ⁵ If yes, have you had any recent chest infections? No ⁰ Yes ⁵ Are you having any new difficulties understanding what people are saying to you? (in your first language) No ⁰ Yes ¹ Have you had any recent difficulty speaking or communicating? No ⁰ Yes ¹ TOTAL SCORE (staff use only)		9. Please tell us what your three most important concerns are: 1..... 2..... 3..... 10. Please CIRCLE the number (0-10) that best describes how much help you need for these concerns. 	
6. NUTRITION In the last three months (please CIRCLE): Have you lost weight without trying? No ⁰ Unsure ² If YES, please tick the amount 1 - 5kg ¹ 6 - 10kg ² 11 - 15kg ³ + 15kg ⁴ Unsure ² Have you been eating poorly because of a decreased appetite? No ⁰ Yes ¹ Do you follow a special diet at home (eg. for diabetes)? No ⁰ Yes ¹ TOTAL SCORE (staff use only)		8. OCCUPATIONAL THERAPY In the last three months (please CIRCLE): Have you experienced difficulties in your ability to carry out everyday activities (e.g. showering, preparing meals, getting in and out of bed, shopping) No ⁰ Yes ¹ Have you experienced fatigue, anxiety and/or pain which has impacted on your everyday activities such as brushing teeth, eating, dressing or working? No ⁰ Yes ¹ Have you had difficulty with remembering things, concentrating, or felt confused and disorientated? No ⁰ Yes ¹ TOTAL SCORE (staff use only)		THANK YOU Staff member: Date of diagnosis: Completed by: PATIENT / NURSE / BOTH Interpreter required: Y / N Information provided: Verbal Information / brochure Other: Referral required: Patient: CONSENTED / DECLINED Refer to:	
Affix patient label or record patient details Surname: First Name: D.O.B: Sex: UR No:					

AlfredHealth



Patient Survey	
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5. The tool helped me think about my needs separate from the treatment I was going to receive.

Rate:

1	2	3	4	5
Strongly				Strongly
Agree				Disagree

Comments:

Rate:

1	2	3	4	5
Strongly				Strongly
Agree			Disagree

Comments:

Comments:

6. I felt that the time spent with the nurse to discuss my treatment and the screening tool was useful.

Rate:

1	2	3	4	5
Strongly				Strongly
Agree			Disagree

Comments:

Rate:

1	2	3	4	5
Strongly				Strongly
Agree				Disagree

Comments:

Comments:

7. I was able to ask questions about the screening tool.

Rate:

	1	2	3	4	5
	Strongly				Strongly
	Agree			Disagree

Comments:

Rate:

1	2	3	4	5
Strongly				Strongly
Agree				Disagree

Comments:

Comments:

8. The room used to speak with the nurse at my first appointment was appropriate.

Rate:

	1	2	3	4	5
	Strongly				Strongly
	Agree	Disagree			

Comments:

Rate:

1	2	3	4	5
Strongly				Strongly
Agree				Disagree

Comments:

Comments:

9. I found the information provided to me appropriate
(verbal or written) (if applicable).

Rate:

	1	2	3	4	5
	Strongly				Strongly
	Agree			Disagree

Comments:

Rate:

1	2	3	4	5
Strongly				Strongly
Agree			Disagree

Comments:

Comments:

10. I found the referrals made to other services appropriate (if applicable).

Rate:

1	2	3	4	5
Strongly				Strongly
Agree			Disagree

Comments:

Rate:

1	2	3	4	5
Strongly				Strongly
Agree				Disagree

Comments:

Comments:

11. Overall, do you have any comments about the supportive care screening tool or the pilot project?

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A joint initiative of Alfred Health, Cabrini Health, Peninsula Health and Southern Health
Connecting cancer care, driving best practice and improving patient outcomes
Page 2 of 2

Attachment 3. Screening tool data analysis

Distress Thermometer scores

Distress score (DS)	n (%)		
0	4(8)	Median	5
1	5 (10)	Mean	4.7
2	4(8)		
3	4 (8)		
4	2 (4)	DS sub-groups	n (%)
5	10(20)	dt ≤3	17 (34)
6	4 (8)	dt ≥4	31 (62)
7	3 (6)	dt (-)	2 (4)
8	7 (14)		
9	3 (6)		
10	2 (4)		
- (incomplete)	2(4)		

Problem Checklist

	dt ≤3		dt ≥4		dt (-)		Total (n=46)	
Practical Problems	n	%	n	%	n	%	n	%
child care	1	5.9	1	3.6	-	-	2	4.3
housing	1	5.9	2	7.1	-	-	3	6.5
insurance / financial	3	17.6	4	14.3	-	-	7	15.2
transportation	3	17.6	5	17.9	-	-	8	17.4
work / school	1	5.9	6	21.4	-	-	7	15.2
Family					-	-		
dealing with children	1	5.9	2	7.1	-	-	3	6.5
dealing with partner	-	-	3	10.7	-	-	3	6.5
Emotional								
depression	1	5.9	21	75.0	-	-	22	47.8
fears	1	5.9	16	57.1	-	-	17	37.0
nervousness	1	5.9	23	82.1	-	-	24	52.2
sadness	3	17.6	15	53.6	-	-	18	39.1
worry	5	29.4	21	75.0	-	-	26	56.5
loss of interest in usual activities	2	11.8	10	35.7	-	-	12	26.1
Spiritual	-	-	2	7.1	-	-	2	4.3
	dt ≤3		dt ≥4		dt (-)		Total (n=46)	
Physical	n	%	n	%	n	%	n	%
appearance	1	5.9	5	17.9	-	-	6	13.0
bathing / dressing	-	-	3	10.7	-	-	3	6.5
breathing	4	23.5	7	25.0	-	-	11	23.9
changes in urination	1	5.9	3	10.7	-	-	4	8.7
constipation	1	5.9	11	39.3	-	-	12	26.1
diarrhoea	-	-	3	10.7	-	-	3	6.5
eating	7	41.2	12	42.9	-	-	19	41.3
fatigue	10	58.8	17	60.7	-	-	27	58.7
feeling swollen	3	17.6	6	21.4	-	-	9	19.6
fevers	-	-	2	7.1	-	-	2	4.3
getting around	1	5.9	4	14.3	-	-	5	10.9
indigestion	-	-	10	35.7	-	-	10	21.7
memory / concentration	4	23.5	9	32.1	-	-	13	28.3
mouth sores	1	5.9	2	7.1	-	-	3	6.5

nausea	3	17.6	7	25.0	-	-	10	21.7
nose dry / congested	2	11.8	4	14.3	-	-	6	13.0
pain	4	23.5	13	46.4	-	-	17	37.0
sexual	-	-	-	-	-	-	-	-
skin dry / itchy	1	5.9	4	14.3	-	-	5	10.9
sleep	4	23.5	18	64.3	-	-	22	47.8
tingling in hands / feet	2	11.8	5	17.9	-	-	7	15.2

Risk factor questions

	dt ≤3		dt ≥4		dt (-)		Total	
	n	%	n	%	n	%	n	%
Previous treatment for emotional problems (n=50)	3	6	9	18	-	-	12	24
Level of support from family and friends (n=50)								
(not at all) 0-2	1	2	1	2	-	-	2	4
3-4	-	-	-	-	-	-	-	-
(moderately) 5-6	2	4	3		-	-	5	
7-8	1	2	4	8	1	2	6	12
(completely) 9-10	13	26	22	44	1	2	36	72
- (incomplete)	-	-	-	-	-	-	1	2
How much help needed to address identified needs								
(can manage by self) 0-2	2	11.8	11	39.3	-	-	13	28.3
3-4	2	11.8	3	10.7	-	-	5	10.9
5-6	5	29.4	4	14.3	1	100	10	21.7
7-8	2	11.8	5	17.7	-	-	7	15.2
(desperately) 9-10	1	5.9	3	10.7	-	-	4	8.7
- (incomplete)	5	29.4	1	3.6	-	-	6	13.0

Abbreviations

AIHW	Australian Institute of Health and Welfare
DH	Department of Health
HOC	Haematology Oncology Clinic, Alfred Health
ICS	Integrated Cancer Services
IOM	Institute of Medicine (USA)
MDT	Multidisciplinary Team Meetings
NBCC	National Breast Cancer Centre
NCCI	National Cancer Control Initiative
NCCN	National Comprehensive Cancer Network (USA)
NICE	National Institute of Clinical Effectiveness (UK)
SC	Supportive Care
SMICS	Southern Melbourne Integrated Cancer Service
VCAP	Victoria's Cancer Action Plan 2008-2011
WBRC	William Buckland Radiotherapy Centre

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