



SACRED HEART
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A FACILITY OF ST VINCENT'S HEALTH AUSTRALIA

The Feasibility and Impact of using the Distress Thermometer and Problem List Screening Tool in Community Palliative Care Populations

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Introduction



- **Diagnosis with a terminal illness is associated with increased psychological distress for patients and caregivers (Galfin et al 2010)**
- **Distress is known to impact on many aspects of patient care**
 - Poor compliance to medications
 - Increased presentations to medical practitioners
 - Impacts on health-related QoL
 - Adverse effect on survival

What is Distress?

Distress in cancer is a “ multifactorial unpleasant emotional experience of a psychological (cognitive, behavioural, emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment” (NCCN V2 2014)

Rationale



- **The study was carried out in response to concerns that our referral rates to social work were low**
- **Were patients being referred appropriately?**

Aim of the Study

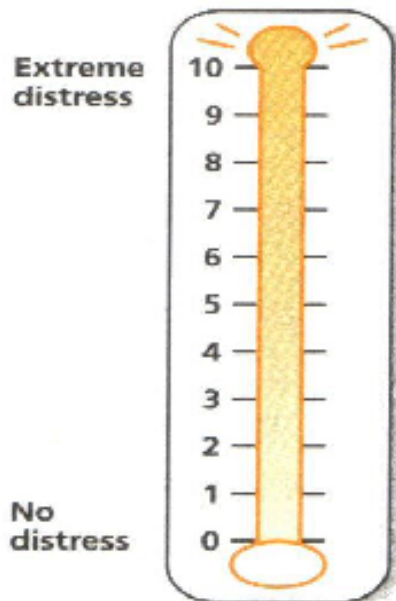
To test the feasibility and impact of using the Distress Thermometer (DT) and Problem List (PL) screening tool to ensure timely identification and referral of patients with self-reported distress to pertinent members of a community based interdisciplinary team

Sacred Heart Community Palliative Care Screening Tools for Measuring Distress

Patient name: _____

Date: _____

First, circle the number (0-10) that best describes how much distress you have been experiencing in the past week including today.



Second, please indicate if any of the following has been a problem for you in the past week, including today. Please be sure to tick YES (Y) or NO (N) for each.

- | | | | | | |
|--------------------------|--------------------------|--|--------------------------|--------------------------|---------------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <u>Practical Problems</u> | <input type="checkbox"/> | <input type="checkbox"/> | <u>Physical problems</u> |
| <input type="checkbox"/> | <input type="checkbox"/> | Child care | <input type="checkbox"/> | <input type="checkbox"/> | Appearance |
| <input type="checkbox"/> | <input type="checkbox"/> | Housing | <input type="checkbox"/> | <input type="checkbox"/> | Bathing/dressing |
| <input type="checkbox"/> | <input type="checkbox"/> | Insurance/financial | <input type="checkbox"/> | <input type="checkbox"/> | Breathing |
| <input type="checkbox"/> | <input type="checkbox"/> | Transportation | <input type="checkbox"/> | <input type="checkbox"/> | Changes in urination |
| <input type="checkbox"/> | <input type="checkbox"/> | Work/school | <input type="checkbox"/> | <input type="checkbox"/> | Constipation |
| <input type="checkbox"/> | <input type="checkbox"/> | Treatment decisions | <input type="checkbox"/> | <input type="checkbox"/> | Diarrhoea |
| | | | <input type="checkbox"/> | <input type="checkbox"/> | Eating |
| | | <u>Family problems</u> | <input type="checkbox"/> | <input type="checkbox"/> | Fatigue |
| <input type="checkbox"/> | <input type="checkbox"/> | Dealing with children | <input type="checkbox"/> | <input type="checkbox"/> | Feeling swollen |
| <input type="checkbox"/> | <input type="checkbox"/> | Dealing with partner | <input type="checkbox"/> | <input type="checkbox"/> | Fevers |
| <input type="checkbox"/> | <input type="checkbox"/> | Ability to have children | <input type="checkbox"/> | <input type="checkbox"/> | Getting around |
| <input type="checkbox"/> | <input type="checkbox"/> | Family health issues | <input type="checkbox"/> | <input type="checkbox"/> | Indigestion |
| | | | <input type="checkbox"/> | <input type="checkbox"/> | Memory/concentration |
| | | <u>Emotional problems</u> | <input type="checkbox"/> | <input type="checkbox"/> | Mouth sores |
| <input type="checkbox"/> | <input type="checkbox"/> | Depression | <input type="checkbox"/> | <input type="checkbox"/> | Nausea |
| <input type="checkbox"/> | <input type="checkbox"/> | Fears | <input type="checkbox"/> | <input type="checkbox"/> | Nose dry/congestion |
| <input type="checkbox"/> | <input type="checkbox"/> | Nervousness | <input type="checkbox"/> | <input type="checkbox"/> | Pain |
| <input type="checkbox"/> | <input type="checkbox"/> | Sadness | <input type="checkbox"/> | <input type="checkbox"/> | Sexual |
| <input type="checkbox"/> | <input type="checkbox"/> | Worry | <input type="checkbox"/> | <input type="checkbox"/> | Skin dry/itchy |
| <input type="checkbox"/> | <input type="checkbox"/> | Loss of interest in usual activities | <input type="checkbox"/> | <input type="checkbox"/> | Sleep |
| | | | <input type="checkbox"/> | <input type="checkbox"/> | Substance abuse |
| <input type="checkbox"/> | <input type="checkbox"/> | <u>Spiritual/religious concerns</u> | <input type="checkbox"/> | <input type="checkbox"/> | Tingling in hands/feet |

Other problems (please specify): _____

Methodology

- **Participants were recruited from a sector of a large specialist community palliative care team**
- **All new referrals over a 6 month period were considered for the study**
- **Eligibility;**
 - Over 18 years of age
 - Cognitive Impairment and able to express their responses through verbal or written communication
 - English speaking background
- **All appropriate new referrals received a hand delivered package from the case manager on the initial visit. This included;**
 - The DT and PL Tool
 - A participant information sheet
 - An acceptability questionnaire and a stamped address envelope

Baseline Characteristics

- **Total number of new referrals over the 6 month study period was 104**
- **71 patients met eligibility criteria**
- **30 patients completed the screening tool**
- **Participants comprised of 14 males and 16 females**
- **Mean age of participants was 74 years (range 49-93)**
- **28 had a cancer diagnosis (5 pancreatic carcinoma (most common))**

Self-reported Levels of Distress



Self-reported distress	No of participants
No distress	3
Mild distress (1-4)	9
Moderate distress (5-7)	12
Severe distress (8-10)	2(3*)
Not answered	3
*One participant rated distress between 6-8	

Most Commonly Reported Problems



Practical Problems- Treatment Decisions

Family Problems- Family Health Issues

Physical Problems- Fatigue, pain and eating.

Only one participants reported any spiritual or religious concerns.

Emotional Problems

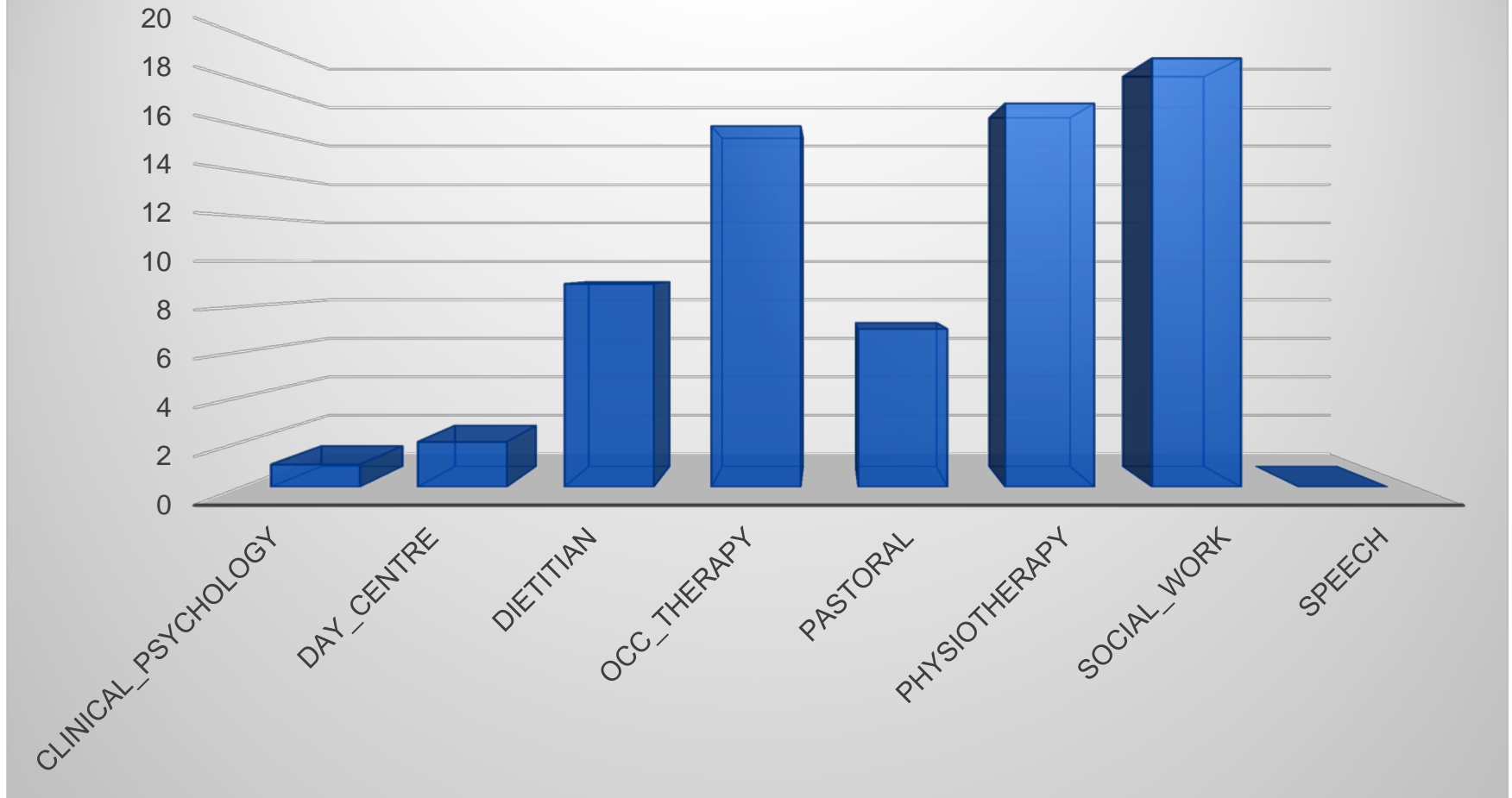
Emotional problems	Number of participants
Depression	10
Fears	11
Nervousness	10
Sadness	14
Worry	15
Loss of interest in usual activities	15

Patient Acceptability of the DT & PL



- 21 participants completed some or all of the questionnaire
- 2/3 found the DT and PL easy to complete
- Mean time taken to complete it was 7.8 mins (2-20)
- Suggested improvements included bigger boxes and an online version to reduce data entry
- Other comments were: fast, good questionnaire, covers a lot of information

Number of Referrals to Each Discipline/Area



Referrals

	Referrals	
	Social work	Clinical psychology
DT study	19/30 (63%)	1 (3%)
Non participants of study	15/41 (36%)	2 (4%)
Pre-study data	32/66 (48%)	4 (6%)

Discussion



- **Implementation of the DT is feasible in this palliative care population**
- **The DT and PL did NOT significantly enhance referral rates to our community based interdisciplinary team**
- **Provide opportunity to openly discuss specific patient related ‘problems’ with our patients**
- **Identifying distress does NOT always correlate with patients wishing to seek referral to interdisciplinary team members**

Discussion

- **Inherent challenges in recruitment in this palliative care population**
 - Patients too unwell/rapid hospitalisation/rapid deterioration
 - Lack of further interest in participating in further trials
 - Poor response rate
- **Good response to the acceptability questionnaire**
- **Few patients reported no distress**
- **Majority of patients reporting distress reported ‘moderate’ distress (4-7)**
- **Most common reported ‘problem’ was fatigue**

Summary



- **Early identification of distress is beneficial**
- **Distress was a common phenomena in this palliative care population**
- **DT and PL was found to be acceptable to our patients**
- **DT and PL did NOT significantly enhance referral rates to interdisciplinary team members**
- **A number of challenges in recruitment of palliative care patients were identified**

References



Fallowfield, L., Ratcliffe D., Jenkins V. and Saul, J. (2001) Psychiatric morbidity and its recognition by doctors in patients with cancer. *British Journal of Cancer* 84 (8)1011-1015.

Galfin JM, Watkins ER, Harlow T. Psychological distress and rumination in palliative care patients and their caregivers. *Journal Of Palliative Medicine*. 2010;13(11):1345-8. PubMed PMID: 21039231.

Howell, D., Brazil, K., Taniguchi, A., Howard, M., Foster, G. and Thabane, L. (2011). A Shared Care Model Pilot for Palliative Home Care in a Rural Area: Impact on Symptoms, Distress and Place of Death. *Journal of Pain and Symptom Management*. 42 (1) 60-75.

Kennard, B., Stewart, S., Olvera, R., Bawdon, R, O hAilin, A., Lewis, C. and Winick, N. (2004). Nonadherence in Adolescent Oncology Patients: Preliminary Data on Psychological Risk Factors and Relationships to Outcome. *Journal of Clinical Psychology in Medical Settings*. 11 (1) 31-39.

Lelorain, S., Bredart, A., Dolbeault, S., Cano, A., Bonnaud-Antignac, A., Cousson-Gelie, F. and Sultan, S(2014). How can we explain physician accuracy in assessing patient distress? A multilevel analysis in patients with advanced cancer. *Patient Education and Counseling*. 94. 322-327.

References



Low, J., Williams, R. and Tookman, A. (2009). Screening for Distress and Depression in Cancer Patients: Is Ultrashort Depression Screening a Valid Measure in the UK? A Prospective Validation Study. *Journal of Pain and Symptom Management*. 38 (2) 234-243.

Maloney, C., Doyle Lyons, K., Li, Z., Hegel, M., Ahles, T. and Bakitas, M. (2013). Patient Perspectives on Participation in the ENABLE 11 Randomized Controlled Trial of a Concurrent Oncology Palliative Care Intervention: Benefits and Burdens. *Palliative Medicine* 27 (4) 375-383.

National Comprehensive Cancer Network. 2013. *NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) for Distress Management (V.2.2013)*. Available: http://www.nccn.org/professionals/physician_gls/pdf/distress.pdf [Accessed 21st August 2013].

Pigott, C., Pollard, A., Thomson, K. and Aranda, S. (2009). Unmet needs in cancer patients: development of a supportive needs screening tool (SNST). *Supportive Cancer Care*. 17, 33-45.

Rhondali, W., Chisholm, G., Daneshmand, M., Allo, J., Kang, D., Filbet, M., Hui, D., Fingeret, M. and Bruera, E. (2013). Association Between Body Image Dissatisfaction and Weight Loss Among Patients With Advanced Cancer and Their Caregivers: A Preliminary Report. *Journal of Pain and Symptom Management*. 45 (6) 1039-1049.

Ryan, D., Gallagher, P., Wright, S. and Cassidy, E. (2012). Sensitivity and specificity of the Distress Thermometer and a two-item depression screen (Patient Health Questionnaire-2) with a "help" question for psychological distress and psychiatric morbidity in patients with advanced cancer. *Psycho-Oncology*. 21 1275-1284.