Developing a Pituitary Distress Thermometer (PDT): a means to improve patient quality of life

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Introduction

- Research has shown that high levels of patient distress may not be identified during consultations with healthcare professionals (HCPs), resulting in significant patient dissatisfaction with care and additional use of primary and secondary care services[1].

- Routinely used in oncology services, the a distress thermometer is a structured way for a nurse or other HCP to discuss with a patient some of the concerns (practical, emotional, physical and psychological) that they may be experiencing.

- A distress thermometer offers patients a list of common difficulties. After the patient has completed the distress thermometer, it can then be used collaboratively by the patient & HCP to discuss options for dealing with the difficulties causing the most distress for the patient.
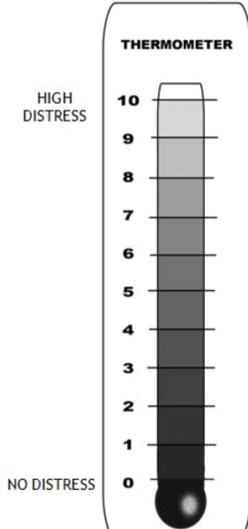
Objectives

Pituitary tumours, though almost always benign, are now included with other central nervous system tumours in cancer services. It therefore seems appropriate to adapt this oncology tool for use with pituitary patients.

Methods

- Working with the Pituitary Foundation, a Wellbeing Survey was generated, comprising 36 pituitary-specific items, plus all 40 items from the Oncology Distress Thermometer (ODT).

- The Survey was posted to all Pituitary Foundation members (n=2,500), enclosed with Pit Life (the magazine of the Pituitary Foundation).

Results

- 901 completed surveys were returned.

- Respondents' age ranged from 18 to 90 years (mean age 59.13±14.25)

- 60% of participants were female

- Hypopituitarism was the most commonly reported diagnosis (43%).

- Multivariate regression modelling was used to determine the symptom clusters associated with the various diagnoses reported by respondents.

- The final analysis generated a 39–item problem-list for the PDT, comprising 32 symptoms, 3 practical problems, and 4 emotional concerns.

- Only one third of Oncology DT items (n=13) appear on the PDT.

- In terms of symptom clusters per pituitary condition, Cushings disease recorded the largest symptom list (n=24 symptoms), while both prolactinoma and non-functioning tumour had the smallest lists (n=4 items).

Results

Figure 1: Front page of the Pituitary Distress Thermometer

Table 1: Symptom clusters by pituitary condition

Pituitary condition	Symptoms (and p value) from Wellbeing Survey
Acromegaly 14 symptoms	Infertility (p<.001); tiredness/fatigue (p<.016); difficulty concentrating (p<.012); dizzy spells (p<.018); sleep apnoea (p<.001); poor temperature regulation (p<.027); constant thirst (p<.010); think skin (p<.013); burn easily in sun (p<.028); appearance (p<.021); constipation (p<.016); medication management (p<.041); nervousness (p<.001); worry (p<.015)
Craniopharyngioma 9 symptoms	Infertility (p<.001); sleep apnoea (p<.023); visual disturbance (p<.022); constant thirst (p<.001); change in appetite (p<.004); more visits to loo (p<.031); burn easily in sun (p<.007); medication management (p<.045); sleep problems (p<.004)
Cushings 24 symptoms	Infertility(p<.012); generally unwell (p<.013); weight gain (p<.001); difficulty concentrating (p<.017); mood swings (p<.006); dizzy spells (p<.023); hot flushes (p<.020); leg pain (p<.033); muscle aches (p<.003); muscle weakness (p<.001); poor temperature regulation (p<.019); back pain (p<.001); hair growth (p<.001); change in appetite (p<.045); thin skin (p<.001); medication management (p<.035); nervousness (p<.032); worry (p<.036); appearance (p<.001); fatigue/tiredness (p<.040); problems getting around (p<.012); pain (p<.006); skin (dry/itchy/greasy) p<.028); tingling in hands/feet (p<.004)
Hypogonadism 7 symptoms	Infertility (p<.001); low libido/sexual desire (p<.001); constant thirst (p<.049); change in appetite (p<.010); problems planning (p<.032); medication management (p<.013); nervousness (p<.028)
Hypopituitarism 9 symptoms	Infertility (p<.001); headaches (p<.005); fatigue/tiredness (p<.001); memory problems (p<.016); sleep apnoea (p<.039); finding it hard to stay awake (p<.012); peer temperature regulation (p<.028); thin skin (p<.014); medication management (p<.001)
Non-functioning tumour 4 symptoms	Infertility (p<.037); leg pain (p<.025); thin skin (p<.029); medication management (p<.048)
Prolactinoma 4 symptoms	Infertility (p<.001); low libido/sexual desire (p<.039); headaches (p<.001); spots (p<.008); loads of dry skin on feet (p<.047)

Table 2 showing the frequency of most commonly reported pituitary conditions for n=901 respondents to the Pituitary Foundation Wellbeing Survey

Pituitary condition	Frequency (percentage)
Hypopituitarism	387 (43%)
Diabetes Insipidus (DI)	178 (19.8%)
Acromegaly	164 (18.2%)
Non-functioning tumour (NFT)	123 (13.7%)
Prolactinoma	118 (13.1%)
Cushings Disease	103 (11.4%)
Craniopharyngioma	48 (5.3%)
Hypogonadism	21 (2.3%)
Other	80 (8.9%)

Conclusions

Many studies using disease-specific questionnaires have demonstrated distress in patients with pituitary disease, which may not be disclosed or discussed during regular consultations[2-6]. The PDT offers a potential solution, as well as illustrating the need for the development of disease-specific distress thermometers and greater knowledge about specific symptom clusters as reported by patients.

References

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