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Fear of Recurrence: it's time for us to do more for patients

How often do we talk about the fear of the cancer coming back to patients and their carers? The evidence is that we don't raise the issue of fear of recurrence often enough during follow-up and this leads to potentially avoidable anxiety and distress. Fear of recurrence is a very sensitive area but clinicians and the wider professional support network can do more to help patients.

Recent evidence for the Patient Concerns Inventory (PCI) [1] is that in head and neck cancer (H&N) [2] (Figure 1) breast cancer [3] (Figure 2), and neuro-oncology [4], fear of recurrence (FOR) is a key issue that patients wish to talk about in their follow-up clinics. It is the most frequent item in PCI-H&N and PCI-breast cancer. In a survey of 447 H&N cancer patient the frequency varied from 32% following advanced oral cancer to 44% in early oropharyngeal cancer [5]. In a survey of 200 breast cancer patient 49% wanted to discuss fear of recurrence, 31% fear of cancer spreading and 25% fear about the future, with 57% raising one or more of these concerns. It is likely that FOR is a concern common to all cancers [6] and that these fears are formed early in treatment. In the past we just have not been able to identify the issue very easily as it is hard to raise the topic in clinic without a prompt from the patient. It tends to be a taboo subject and the simplest way the patient and the clinician tackle the matter is just not to mention it. Those patients wishing to raise the topic in clinics via the PCI are unpredictable by stage of disease, radicality of treatment, time since treatment, likelihood of recurrence [7,8]. Older patients are less prone to FOR problems. Patients with early H&N cancers treated many years before, though from the clinical perspective have very low recurrence risk, can still have FOR hence there is value in allowing patients to express these concerns via a prompt such as the PCI. Clinicians should not underestimate the reluctance of patients raising this issue with them. Patients seem acutely aware of the pressures that oncology teams are under to deliver cancer care efficiently and therefore do not wish to raise an issue that might delay the clinic schedule. The patient may also feel somewhat ashamed to raise a delicate issue that may challenge the ethos of the treatment strategy functioning as a permanent cure. The discomfort of inspecting a non-ideal result of the care and attention received such as a recurrence is felt acutely by the patient who does not wish to disappoint the health care team by inadvertently stumbling onto territory that questions positive treatment outcomes.

Though it is understandable and to some degree acceptable as a normal reaction to having been

treated for cancer it is important to gain an awareness from patients about the level of FOR that they commonly experience. This is highlighted in research evidence that strongly suggests that, in some patients, FOR is associated with substantial psychological morbidity [7,9]. In the breast cancer PCI those patients expressing more than three fears had significant distress. In those patients with H&N cancer raising the issue of FOR on the PCI, 79% had significant problems compared to 24% if they did not [7]. The current understanding of FoR levels across various cancer sites shows a strong similarity of intensity. However prostate cancer patients tend to have lower levels of FoR compared to breast, lung and colorectal cancer patients. The greatest functional impact of FoR was found in lung cancer patients. Some patients with high levels of FoR show some characteristics of thoughts becoming intrusive and uncomfortable [10]. This type of thinking showed evidence of not being able to dismiss the content about the possibility of the cancer returning. This intrusive thinking was regarded as an area requiring some specific attention from trained personnel to assist patients.

The mechanism of how high levels of FOR may be linked to distress and, in particular, to depression is not well understood. The associations are relatively high and theoretically various convincing psychological models can be proposed that would explicate a causal connection [11]. The manifestations of enhanced FOR are expressed by excessive checking, over-vigilance, intrusive FOR thoughts frequently during the day, poor sleep, and anxiety. There is likely to be a hidden cost to persistent FOR. Not only poorer quality of life [12], delayed adaptation (time off work), but also more frequent hospital attendances, and unnecessary investigations [13]. Once identified the provision of key information during the consultation is often all that is required. Information giving around risk, normalising the experience of FOR, empathy and basic counselling will be sufficient for the majority of patients (Table 1). Patient information leaflets are available focused on the issue of FOR [14]. Although there are several useful websites (Table 2) there is still probably a need for refinement in order to have a resource that more fully meets the needs of patients. From clinical experience, various survey and qualitative investigations show that some patients, perhaps around 20%, have sufficient difficulties associated with FOR that they would need formal referral for emotional support or cognitive therapy to be delivered by staff with a special interest in emotional issues, counselling staff or clinical psychologists. Although various therapies will have potential generic benefit such cognitive behavioural therapy or mindfulness-

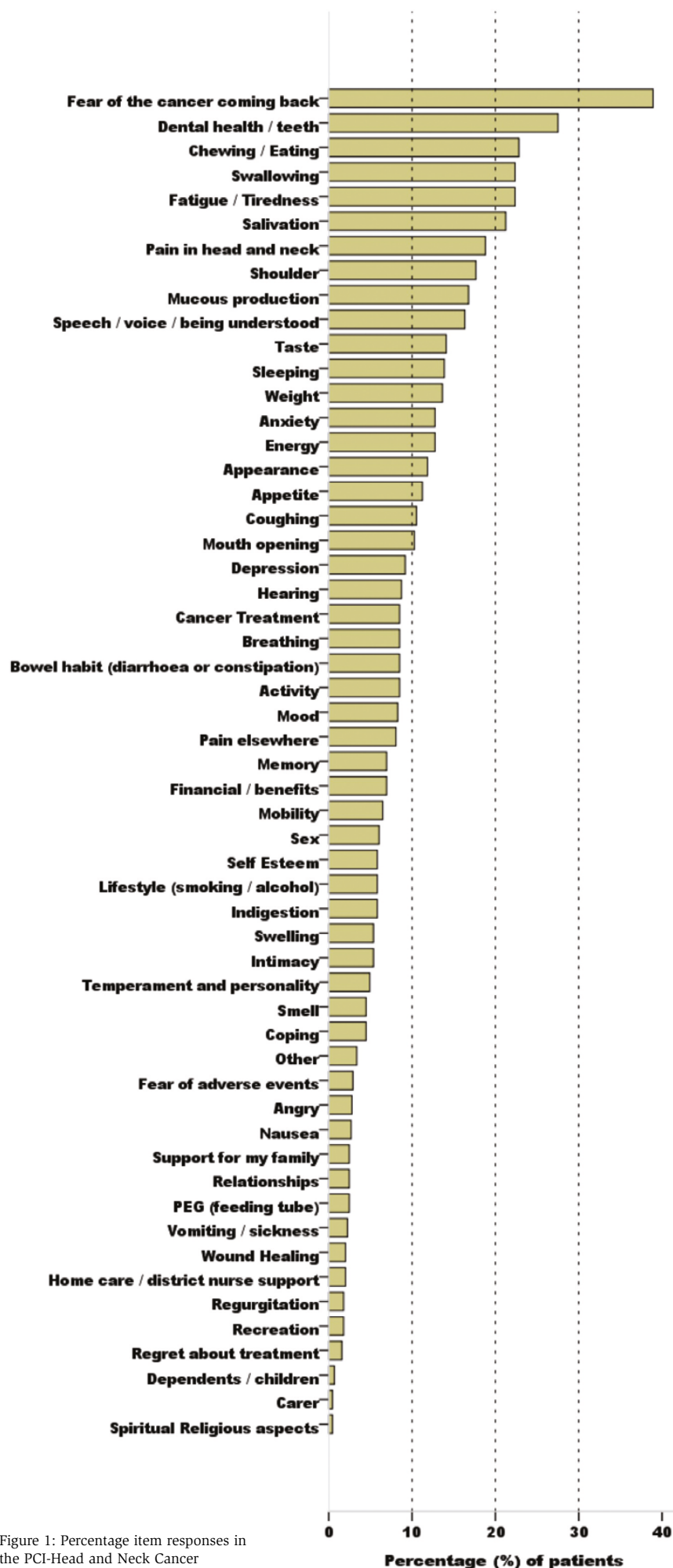


Figure 1: Percentage item responses in the PCI-Head and Neck Cancer (n = 447 patients).

based interventions, there is some evidence that suggests more specific intervention around recurrence fears would be appropriate [11]. Such an intervention is the AFTER intervention, Adjustment to the Fear, Threat or Expectation of Recurrence [15]. This structured intervention targets recurrence fears, inappropriate checking behaviour, and beliefs about cancer, adopting recognised cognitive behavioural and health psychology principles, particularly Leventhal's self-regulation model. The intervention focuses on reducing anxiety (through exposure to the fear of recurrence) and purports to prevent long term psychological distress and promote patients ability to self manage.

The AFTER intervention can be framed within the context of busy NHS practice through the delivery of a mini AFTER delivered in part by individuals with counselling training and advanced communication skills. The mini AFTER is being designed for a trained staff member of the oncology team to conduct in a single session lasting about 30 minutes. It aims to assess the FOR level and determine the triggers of FOR and how the patient currently attempts to manage the fear. At moderate levels this very brief intervention will perform three functions: (i) signal to the patient that their fears are reasonable and can be understood (ii) identify the main components that have raised these fears and present some possible explanations for their intrusiveness and inability to cope with them, finally (iii) provide patients and any accompanying carers the opportunity to discuss potential ways to address these fears in a practical and easy to follow manner. It is reasonable to target the intervention for both the patient and the carer. Carers have been shown to exhibit FOR, and on average show levels that are as high if not higher than the persons they are supporting who are being treated for cancer. Some evidence exists that there is a close association between carers and patients FOR [16]. This work has led some investigators to state that the management of concerns about cancer coming back' is one of the top ranking unmet needs across time included amongst carers [17].

Patients with more extensive and deeper seated FOR may require a more elaborated input from the team. The more intensive AFTER intervention consisting typically of six sessions can be offered. This intervention is being developed from the initial

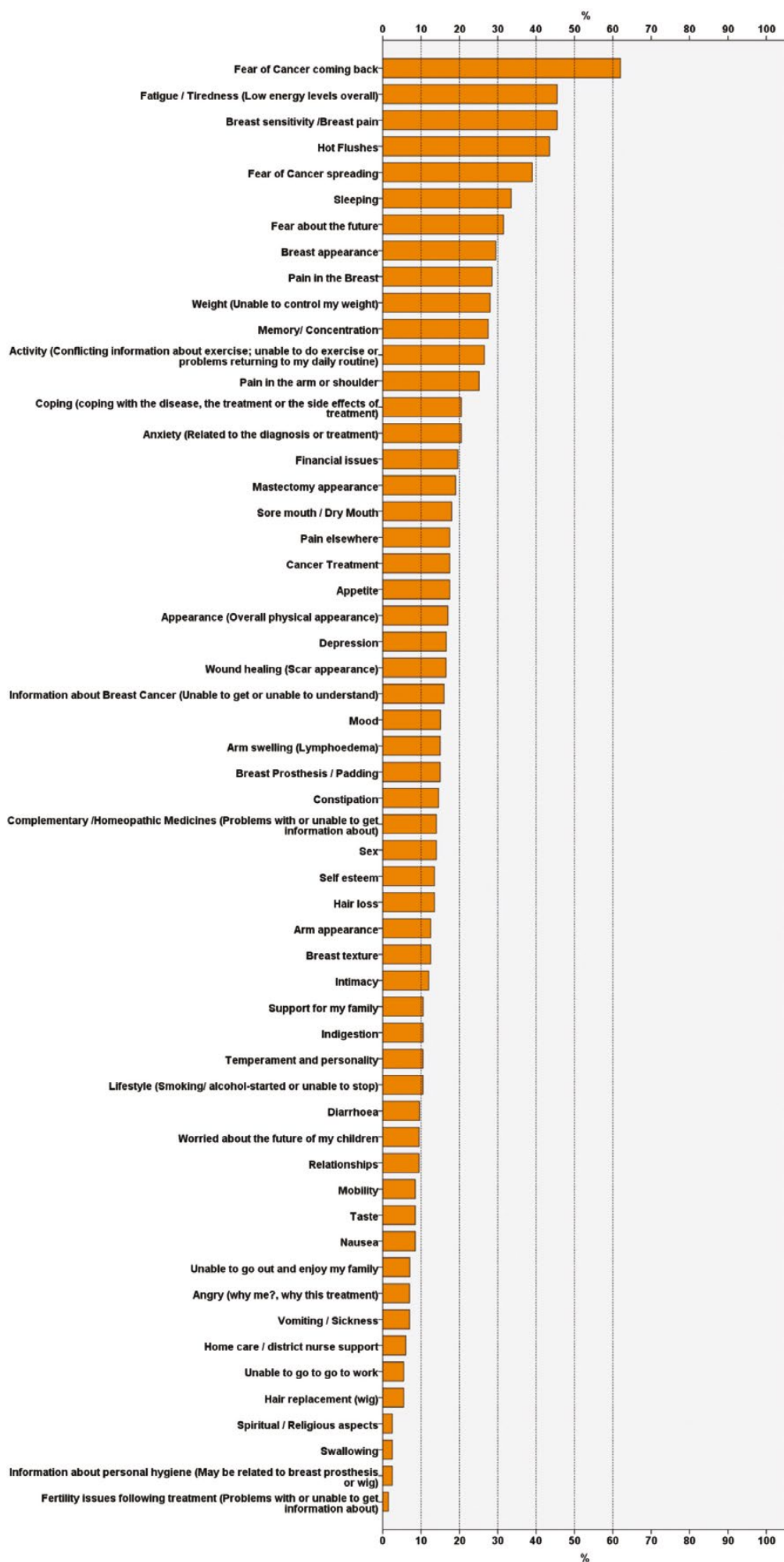
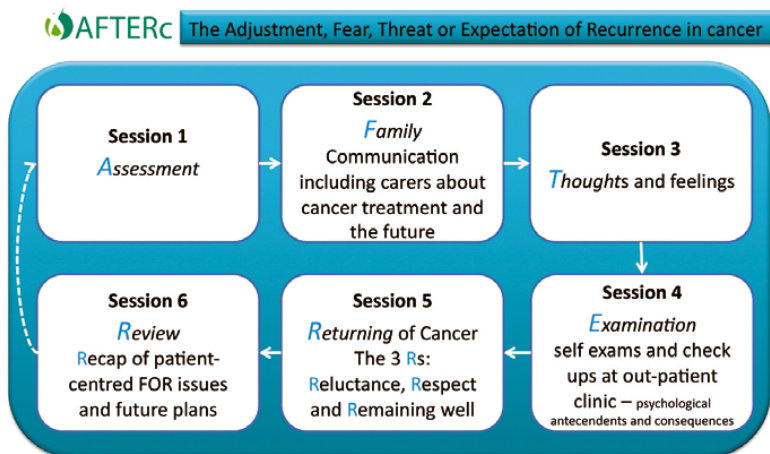


Figure 2: Percentage item responses in the PCI-Breast Cancer (n = 200 patients)

research work by Humphris and colleagues, first at Liverpool and more recently at St Andrews/Edinburgh and NHS Fife. It is intended that the intervention will be available shortly through web access under a registered low cost licence scheme for interested professionals. The elements of the intervention are listed in Box 1 below. More research is required as to how to most cost effectively deliver such intervention and this lends itself to a well designed randomised trial. ■

Box 1: Outline of AFTER intervention.



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Table 1: Points around advice on fear of recurrence.

Patients should be confident to raise the issue with their cancer team as it is such a common issue. Although it can be a taboo subject but it is better to discuss it.

Questions patients might wish to ask at any stage during their cancer care but usually after treatment has been completed and acute side effects are fading and a 'new normal' is emerging. Patients need to be reassured that FOR is normal and potentially a positive feeling as it promotes self checking.

Information around recurrence should be tailored to the cancer site.

The clinical team should be able to cover aspects such as:

1. what are the chances of the cancer coming back
2. when is the cancer most likely to come back
3. where is it most likely to come back to
4. what are the symptoms and the things to look out for
5. do investigations such as scans or blood tests give more certainty that recurrence is less likely
6. what can be done if it comes back
7. what is the outlook (chance of cure)
8. when can their be confidence that there is cure (e.g 5 years, 10 years, never)
9. who do I contact if the patient think the cancer is coming back- contact the clinic, consultant secretary, CNS, open access
10. what guide is there to self help e.g discussion around patient information leaflets material available in clinic
11. let others know, the wider team and the GP
12. can I get specialist support e.g AFTER intervention

Table 2: Useful websites.

<http://cancer.about.com/od/copingwithcancer/f/How-So-I-Cope-With-The-Fear-Of-Cancer-Recurrence.htm>

<http://cancer.about.com/od/copingwithcancer/f/How-So-I-Cope-With-The-Fear-Of-Cancer-Recurrence.htm>

<http://www.cancer.net/coping/emotional-and-physical-matters/coping-fear-recurrence>

<http://www.cancer.org/treatment/survivorshipduringandaftertreatment/understandingrecurrence/livingwithuncertainty/living-with-uncertainty-toc>

<http://www.dana-farber.org/For-Adult-Cancer-Survivors/Experts-Speak-on-Survivorship-Topics/Fear-of-Cancer-Recurrence.aspx>

<http://www.headandneckcancer.co.uk/For+patients/Problems+and+Solutions/Fear+of+Recurrence.aspx>

<http://www.livestrong.org/Get-Help/Learn-About-Cancer/Cancer-Support-Topics/Emotional-Effects-of-Cancer/Fear-of-Recurrence>

<http://www.mayoclinic.com/health/cancer-recurrence/MY01877>

<http://www.webmd.com/breast-cancer/guide/coping-with-fear-of-recurring>