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# Health-related quality of life, fear of recurrence, and emotional distress in patients treated for thyroid cancer

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## Abstract

Diagnosis of differentiated thyroid carcinoma (papillary or follicular) and its treatment may be associated with a poor health-related quality of life (HRQoL), and with fear of recurrence (FoR), and distress. To our knowledge, this is the first time a single FoR screening question (written to complement a HRQoL questionnaire), has been reported with HRQoL and levels of distress in patients treated for the disease. In April 2014 we did a cross-sectional survey of patients who had presented to the Merseyside and Cheshire thyroid cancer network between April 2009 and November 2013. Questionnaires comprised the European Organisation for Research and Treatment of Cancer (EORTC) QLQ-C30, the THYCA-QoL, the Emotion Thermometers, and the new FoR screening item. A total of 249 surveys were sent and 169 patients responded (68%). The most prevalent issues included tiredness, problems with sleep and needing to rest, pain (particularly in muscles and joints), a dry mouth, hot flushes and tolerating heat, gaining weight, and feeling slowed down or weak; also, having trouble taking long walks or doing strenuous activities, feeling tense, worried, irritable, and anxious, and having difficulty remembering things. One in seven patients (95% CI 9% to 21%) responded to the single FoR question that they “had a lot of fears of recurrence that really preoccupied their thoughts” or were “fearful all the time that their cancer might return and that they struggled with this”. Distress overall was relatively low. In conclusion, the HRQoL issues reported by these patients were different from those reported by patients with other cancers of the head and neck. It would be helpful to identify FoR in a subgroup of patients with differentiated thyroid cancer so that they could be given additional support.

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**Keywords:** Thyroid Cancer; Patient Reported Outcomes; Health-related quality of life; Fear of recurrence

## Introduction

A recent systematic review,<sup>1</sup> which reported health-related quality of life (HRQoL) among survivors of differentiated

thyroid carcinoma, identified 27 articles published between 1997 and 2010. These and more recent publications suggest that HRQoL in this group is similar to or slightly worse than that of the normative population, but patients have specific medical problems.<sup>1–5</sup> These include fatigue, scarring, dysfunction after neck dissection, salivary morbidity after treatment with radioactive iodine, persistent restrictions in returning to normal daily activity, dysphonia after thyroidectomy, and emotional distress.<sup>6</sup> Not all patients are affected to the same degree, but short-term hypothyroidism severely impairs HRQoL.<sup>7</sup> Women, those who were young

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at diagnosis, and those with a low educational attainment, are associated with a poorer HRQoL.<sup>8</sup>

Although differentiated thyroid carcinoma has an excellent prognosis, almost half of patients, even 15 years after diagnosis, were worried about recurrence, and this worsened their psychological distress and lowered their HRQoL.<sup>9</sup> Fear of recurrence (FoR) is a universal concern in people who have had cancer,<sup>10</sup> and is one of the most prevalent areas of unmet need.<sup>11</sup> A systematic review by Koch et al<sup>12</sup> indicated that it persists for a long time after initial diagnosis, and it has a substantial effect on the quality of life of patients with thyroid cancer.<sup>13</sup> Roerink et al<sup>6</sup> reported a high prevalence of distress among patients even after long-term remission, and emphasised the need for routine screening for distress to identify the problem, manage it, and consequently reduce its impact on HRQoL.

As FoR cannot be predicted by clinical characteristics alone,<sup>14</sup> we report use of a simple single screening question on FoR with existing questionnaires on HRQoL and distress, in patients treated for differentiated thyroid carcinoma.<sup>15,16</sup> To our knowledge, this is the first study to report its use in this context.

## Method

In April 2014 a survey of patients treated for differentiated thyroid carcinoma was conducted by the thyroid multidisciplinary team in Merseyside and Cheshire. Reminders were sent out in June 2014. Patients were eligible if they had had ablation with radioactive iodine, with or without operation, between April 2009 and November 2013, and were aged over 18, disease-free, and alive at the time of the survey.

The survey comprised various questionnaires: the European Organisation for Research and Treatment of Cancer (EORTC) QLQ-C30,<sup>17</sup> a thyroid supplementary questionnaire,<sup>18</sup> questions about FoR,<sup>14</sup> the single-item question,<sup>16</sup> and the Emotion Thermometers.<sup>19</sup> The EORTC QLQ-C30 was used to assess HRQoL across five functional domains, three symptom scales, a global health domain, and six single items. A 24-item thyroid-supplementary questionnaire (THYCA-QoL) was used to assess thyroid-specific symptomatology. Items in this are scored on a four-point scale (1: not at all, to 4: very much), except global health status, which uses a seven-point scale (1: very poor, to 7: excellent). The FoR inventory (seven-item questionnaire) has been used in previous studies on head and neck cancer, and this, together with the single FoR question, focus on the fears and worries associated with the risk of recurrence, and measure their impact on daily life. Items are scored on a five-point scale (1: not at all, to 5: all the time). The Emotion Thermometers tool consists of five visual analogue scales (0-10) with four emotion domains (distress, anxiety, depression, anger) and one that concerns the need for help.

We followed the EORTC QLQ-C30 protocol to transform EORTC items into scales, and adapted this approach for items

in the thyroid supplementary questionnaire. Spearman's correlation was used to measure the strength of association of the scales of the EORTC and thyroid questionnaires with age, time from treatment, FoR, and Emotion Thermometer scores. The Mann-Whitney test was used to test the association of these scales with the type of cancer (follicular, papillary), p-stage (1-2, 3-4), and sex. The chi square or Fisher's exact test were used to test for association between clinical characteristics and response to the survey. Because of the many tests done, we regarded probabilities of less than 0.01 as significant.

## Results

A total of 169/249 patients responded (68%). The sample was largely female (180/249, 72%), and the median (IQR) age at survey was 51 (40-63) years. The cancer was papillary in 188 (76%), follicular in 54 (22%), and unknown in 7 (3%). Overall, disease was stage 1-2 in 170 (68%), stage 3-4 in 67 (27%), and unknown in 12 (5%). The median (IQR) time from first treatment to survey was 31 (19-46) months. The response rate was lower in younger patients: 23/62 (37%) under 40 years, 33/49 (67%) aged 40-49, 71/88 (81%) aged 50-64, and 42/50 (84%) aged 65 or over ( $p < 0.001$ ). Fewer responses came from those with stage 1-2 disease (106/170 (62%) compared with 56/67 (84%) of those with stage 3-4), although this was confounded by the staging process that defines the grades either side of 45 years. There were no other notable variations in response by sex, type of cancer, or time from treatment.

Three-quarters of the statements on the EORTC QLQ-C30 (Tables 1A and 1B) and supplementary thyroid questionnaires (Table 2) were experienced "quite a bit" or "very much" by at least 10% of patients. The most prevalent problems with HRQoL (affecting 17%-34% "quite a bit" or "very much") included tiredness, trouble with sleeping and needing to rest (items E10, E11, E18, and T19), pain, particularly in muscles or joints (E9, T10), dry mouth (T1), hot flushes and tolerating heat (T8, T9), gaining weight (T14), feeling slowed down, weak, or having trouble taking long walks or doing strenuous activities (E1, E2, E12, T13); also, feeling tense, worried, irritable, or anxious, or having difficulty remembering things (E21, E22, E23, E25, T23). In answer to the single FoR question, one in seven patients (23/162, 14%, 95% CI 9% to 21%) responded that they had "a lot of fears of recurrence that really preoccupied their thoughts", or were "fearful all the time that their cancer might return and that they struggled with this" (Table 3). One third (56/162, 35%) responded that they sometimes had fearful thoughts but could usually manage them. Across the seven-item statements on the FoR inventory, 10%-19% of patients had these experiences "a lot" or "all the time", with 50/168 (30%) experiencing one or more items, and 25/168 (15%) at least three. In regard to the Emotion Thermometers (Table 3), 22/168 (13%) had a distress thermometer score of four or more. Rates for scores of four

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