Long-Term Worry After Early-Stage Breast Cancer Diagnosis: Longitudinal Study of a Population-Based Cohort

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Introduction

- Worry about recurrence influences treatment decision-making, surveillance behaviors, and quality of life of people with cancer.[1-3]
- The long-term experience of worry among patients with early-stage breast cancer requires better understanding and validated instruments for efficient measurement.

Methods and Materials

- ICanCare enrolled 2502 women with early-stage breast cancer, diagnosed in 2014-15 and reported to Georgia and Los Angeles registries, who responded to surveys in the year of diagnosis (T1).
- After excluding those deceased, too ill, or otherwise unable to participate, 2361 were sent follow-up surveys in 2021-22 (T2), of whom 1412 responded.
- A scaled measure across 3 items was developed using factor analysis and evaluated for internal consistency and validity in bivariate analyses with tumor and patient characteristics, using Wilcoxon/Kruskal-Wallis tests for all variables (categorical) except age (continuous), which was compared using Spearman's correlation. The 3-item scale was also compared using Spearman's correlation to a single item asking, "In the past month, how often have you worried about your breast cancer coming back?"

In the past month, how often have you worried about your breast cancer coming back?				
☐ Almost never	☐ Rarely	☐ Sometimes	☐ Often	☐ Almost always

During the past month, how often has worrying about your breast cancer coming back				
… made you feel upset?				
… made it difficult for you to carry out your usual daily activities at home or at work?				
… made you feel distant from family and friends?				
☐ Almost never	☐ Rarely	☐ Sometimes	☐ Often	☐ Almost always

Figure 1. During the past month, how often has worrying about your breast cancer coming back made you feel upset?

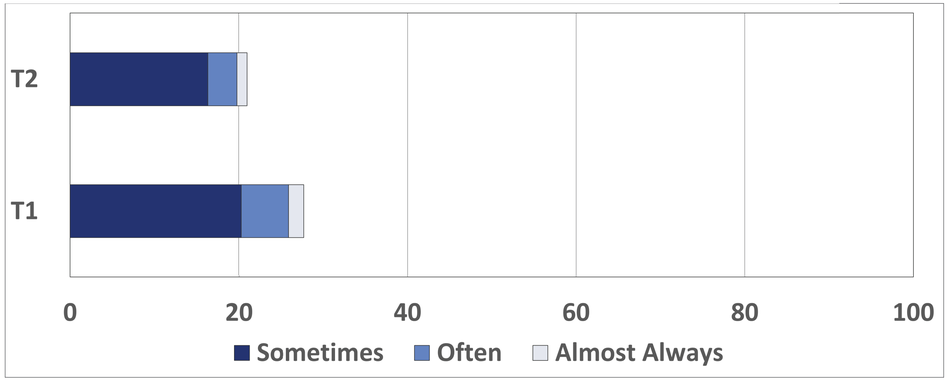


Table 1: Responses of 1165 Participants Without Recurrence or Second Cancer at T2

	Made upset		Impaired daily activities		Affected relationships	
	T1	T2	T1	T2	T1	T2
Almost never	561 (49.4%)	670 (59.0%)	758 (66.8%)	892 (79.4%)	767 (67.8%)	905 (80.2%)
Rarely	260 (22.9%)	226 (19.9%)	222 (19.6%)	151 (13.4%)	196 (17.3%)	132 (11.7%)
Sometimes	230 (20.3%)	185 (16.3%)	110 (9.7%)	63 (5.6%)	122 (10.8%)	74 (6.6%)
Often	64 (5.6%)	40 (3.5%)	28 (2.5%)	11 (1.0%)	29 (2.6%)	13 (1.2%)
Almost Always	20 (1.8%)	14 (1.2%)	16 (1.4%)	7 (0.6%)	17 (1.5%)	4 (0.4%)
Missing	30	30	31	41	34	37

Results

- Over 1 in 5 respondents (27.6% at T1 and 21.1% at T2) endorsed that worry about their cancer coming back made them feel upset at least sometimes in the past month. (Figure 1)
- Factor analysis retained a one-factor solution. Cronbach's alpha for the scale was 0.87 at T1 & 0.82 at T2.
- Scaled scores had mean (SD) of 1.64 (.83) at T1 and 1.43 (.67) at T2; median (IQR) 1.33 (1.00-2.00) at T1 and 1.00 (1.00-1.67) at T2.
- Scaled scores were higher among patients with higher stage (p=.009 at T1 and .007 at T2) and those who were younger (p<0.001 at T1 and T2), Asian and Latina (p<.0001 at T1 and T2), with lower education (p=.003 at T1, p<0.0001 at T2), divorced/separated or never married (p=.0007 at T2 only), and with lowest income (p=.002 at T2 only).
- At T1, the mean score on the single item was 2.16 (SD 1.13), with 37.8% worrying sometimes or more; at T2, the mean was 2.1 (SD 1.08), and 38.3% worried sometimes or more.
- The 3-item scale correlated with the single item (correlation coefficients T1: .71, p<.001; T2: .67, p<.001).

Discussion

- Three-item and single-item measures of worry appear valid for assessing patients with early-stage breast cancer, suggesting that over 1 in 5 patients has worries that extend well beyond 5 years after diagnosis.
- Recognizing patient and tumor characteristics associated with long-term worry may help target resources and supportive interventions.

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