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PROgress Tracker Breast Cancer Registry: Worry of Illness from a Longitudinal Peer-Led, National Patient-Reported Outcomes Registry

Abstract 11112

Shaniah Leduc R.N., Kimberly Carson, Dr. Alison Allan

Results

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A higher proportion of patients with TNBC reported high worry, and younger patients (≤50 years) reported consistently higher worry across all three measures

Table 1: Overall High Worry Proportion n=186

	Number	Mean Score	% High Worry
FACT-B Question			
CW: Condition will worsen	184	1.45	17.4%
HR: Family will get illness	183	2.07	40.4%
SI: Stress will impact disease	186	1.80	31.7%

Figure 2. High Worry % by Cancer Stage (N=180)

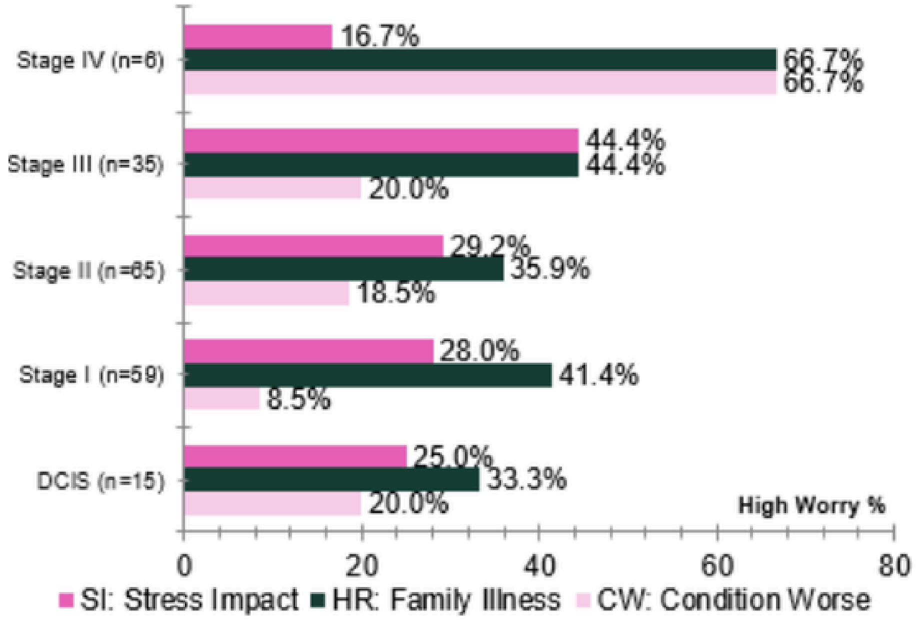
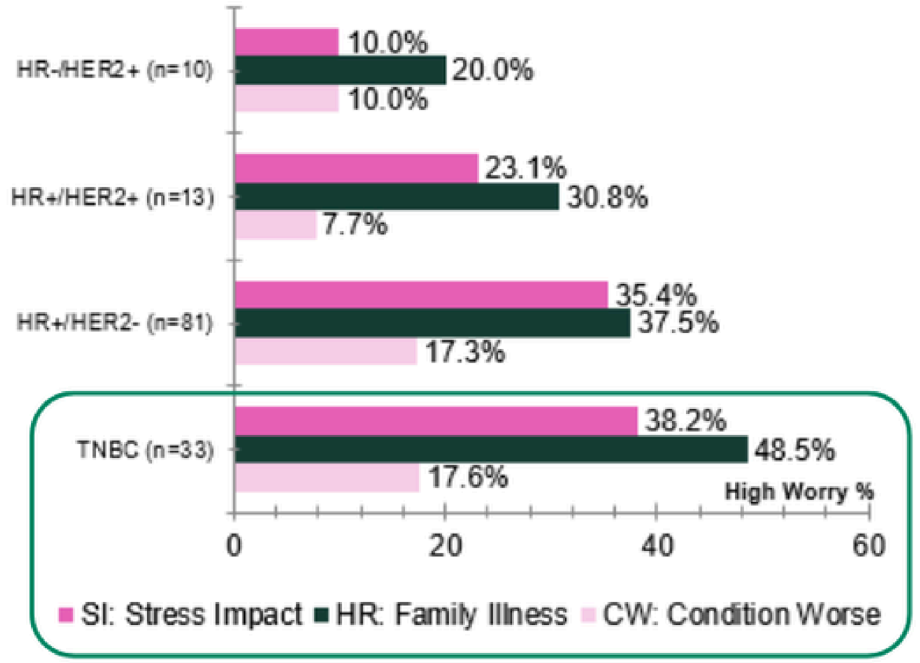


Figure 3. High Worry % by Molecular Subtype (N=138)



Results

Longitudinal analysis demonstrates that elevated recurrence-related worry diminishes following initial treatment but resurges at 18 months, suggesting a biphasic pattern of psychosocial distress.

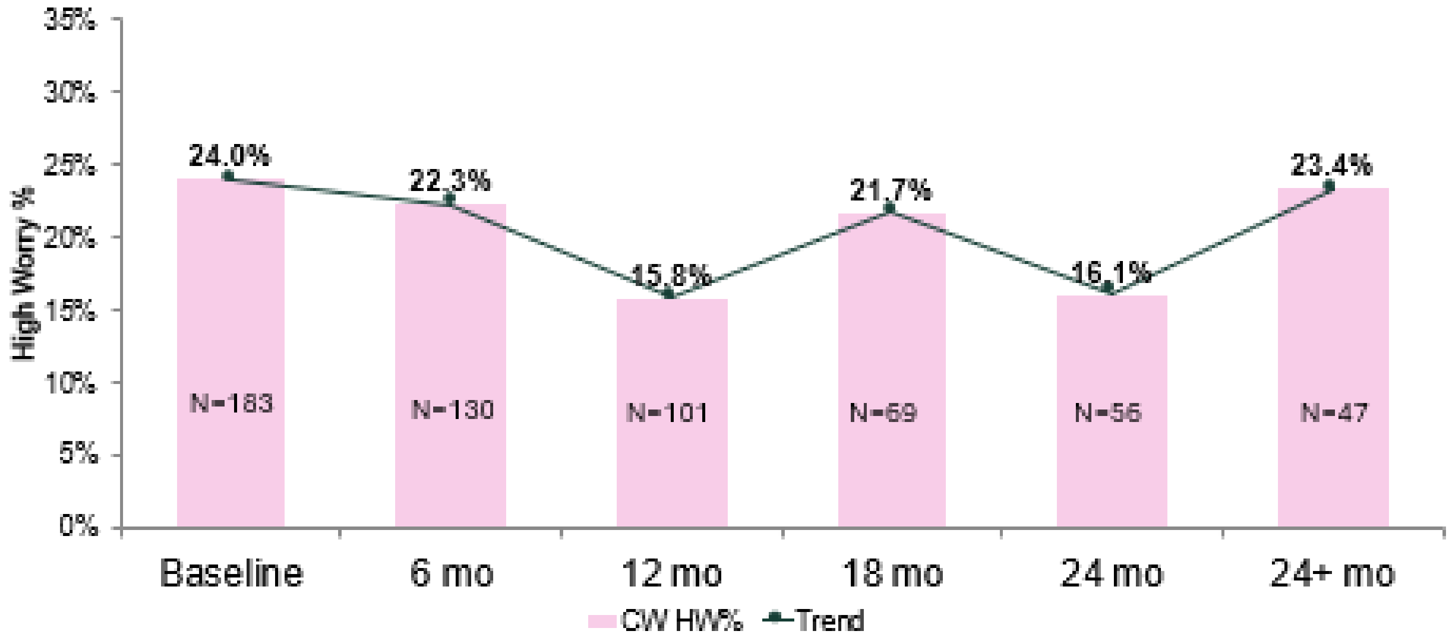


Figure 5. High Worry % Over Time Condition Worsening

Acknowledgements

We gratefully acknowledge **the patients** participating in the Registry with a **10-year commitment** providing long-term patient powered research on their lived experience.

We also gratefully acknowledge research funding provided by individual donors to Breast Cancer Canada, as well as research grants from **AstraZeneca Canada, Gilead Sciences Canada, Novartis Canada, and The Hecht Foundation.**

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PROgress Tracker Breast Cancer Registry: Worry of Illness from a Longitudinal Peer-Led, National Patient-Reported Outcomes Registry

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BACKGROUND

- PROgress Tracker Breast Cancer Registry is a national, longitudinal, non-interventional PROM registry that launched in October 2023 in Canada to capture the lived experience of breast cancer patients. The Registry is directed by Breast Cancer Canada, a registered non-profit, patient-led organization.
- Cancer recurrence-related worry is a significant psychosocial burden for breast cancer survivors that may presist well beyond treatment.[1]
- We sought to analyze cancer recurrence-related worry among breast cancer patients enrolled in the PROgress Tracker Registry by age, stage, and molecular subtype, using FACT-B, a validated PROM that captures three worry dimensions.[2]

METHODS

Study Population

- 186 patients from PROgress Tracker Registry were eligible with ≥2 years tenure and ≥1 FACT-B assessment (of 823 patients in the Registry)

Analysis Approach

- Patient-level data using most recent FACT-B assessment
  - Condition Worsening (CW): "I worry my condition will get worse"
  - Hereditary Risk (HR): "I worry family members might get the same illness"
  - Stress impact on Illness (SI): "I worry about the effect of stress on my illness"
- High Worry defined as score ≥3 on 5-point (0-4) Likert scale (Quite a bit / Very much)

Stratification Variables

- Age at Registry entry ≤50 vs. >50 years)
- Cancer stage (DCIS, Stage I-IV)
- Molecular subtype (TNBC, HR+/HER2-, HR+/HER2+, HR-/HER2+)
- Combined age + stage analysis

RESULTS

Family illness of Hereditary Risk (HR) concern had the highest proportion of overall respondents reporting high worry (40.4%)

Table 1. Overall High Worry Proportion (N=186)

	Number	Mean Score	% High Worry
FACT-B Question			
CW: Condition will worsen	184	1.45	17.4%
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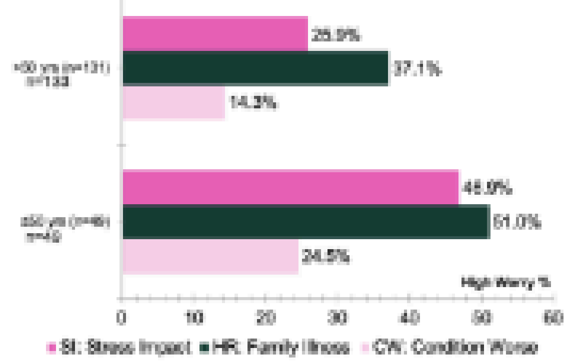
Longitudinal analysis demonstrates that elevated recurrence-related worry diminishes following initial treatment but resurges at 18 months, suggesting a biphasic pattern of psychosocial distress.

A higher proportion of patients with TNBC reported high worry, and younger patients (≤50 years) reported consistently higher worry across all three measures.

RESULTS CONTINUED

Figure 1. High Worry % by Age Category (N=182)



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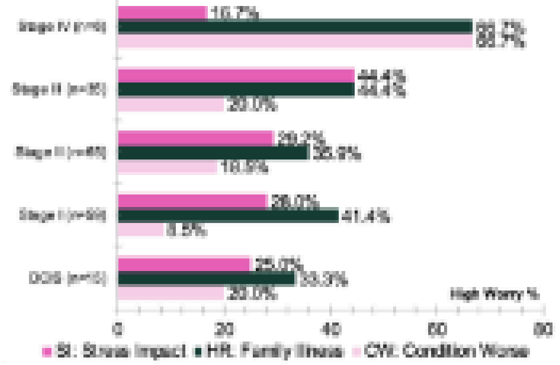
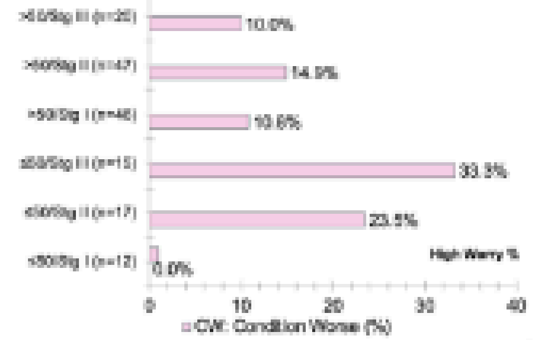


Figure 3. High Worry % by Molecular Subtype (N=138)

Figure 4. High Worry % Condition Will Worsen: Combined Age + Stage Analysis (Stages I-III) (N=157)



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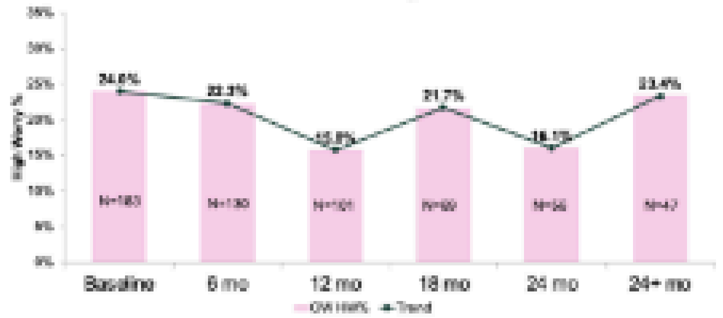

CONCLUSIONS

- These findings inform psychosocial screening, care resources, and genetics education across survivorship.
- Family illness worry (40.4%) was over 2x the rate of disease progression worry (17.4%)
- Younger patients ≤50 years, reported higher worry across all three measures compared to those >50 years
- TNBC patients showed elevated family concern (48.5%)
- High worry decreased at 12 months post-treatment but rose at 18 months, possible linked to surveillance milestones or transitions in care

FUTURE DIRECTION FOR ANALYSIS

- The PROgress Tracker Registry aims to center the patient voice and lived experience in transofmring breast cancer management. Future data analyses will explore:
  - Hereditary Risk worry among BRCA1/BRCA2 carriers compared with non-carriers
  - Relationship between endocrine therapy discontinuation and longitudinal worry about disease progression
  - Worry trajectories over time and their long-term impact on resilience, self-efficacy, and quality of life

ABBREVIATIONS

CW: Condition Worse; HR: Hereditary Risk; SI: Stress Impact; DCIS: Ductal Carcinoma In Situ; FACT-B: Functional Assessment of Cancer Therapy – Breast; HER2: Human epidermal growth factor receptor 2; HR: Hormone receptor; PRO: Patient-reported outcome; PROM: Patient-reported outcome measures; TNBC: Triple-negative breast cancer

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1. Renna ME, Rosie Shrout M, Madison AA, et al. Worry and rumination in breast cancer patients: perseveration worsens self-rated health. J Behav Med. 2021;44(2):253-259. doi:10.1007/s10865-020-00192-9
2. FACIT Home | Licensing and Translation Services | United States. FACIT Group. Accessed May 6, 2026. https://www.facit.org

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