

# Understanding the causes of distress in breast cancer patients and survivors.

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# Distress prevalence in cancer

- Cancer population point prevalence distress estimates vary by time and method
  - 32% (Mehnert et al, 2014) – 78% (Lam et al, 2007)
- Common psychiatric disorder prevalence in cancer population.
  - Mixed cancer diagnoses
    - Anxiety disorder 9-18%; Depressive disorder ~6% (Mehnert et al, 2014) (Germany, 4 week prevalence, n=2,141,).
  - Breast cancer
    - Anxiety 22%; Mood disorder 33% (Hung et al, 2013) (Taiwan, case-control (PP))
  - “long-term survivors” (Meta analysis, 43 studies)
    - Anxiety disorder 17.9% (95%CI 12.8-23.6%); Mood disorder: 11.9% (95%CI 7.7-16.2%) (Mitchell, et al, 2013),
  - Healthy controls:
    - Anxiety 13.9% (95%CI 9.8-18.5) Depression 10.2% (95%CI 8.0-12.6%) ()
    - Approximates to general population lifetime prevalence (Kessler, et al, 2009)

- Active phase of illness trajectory

- Major depression (16%)
- Anxiety (10%)

Mitchell, Chan, Bhatti, et al., 2011

- Survivorship (at least 2 years post-diagnosis)

- Major depression (11.6%)
  - Healthy controls (10.2%)
- Anxiety (17.9%)
  - Healthy controls (13.9%)

Mitchell, Ferguson, Gill, et al., 2013

- Palliative settings

- Major depression (14.3%)
- Anxiety (9.6%)

Mitchell, Chan, Bhatti, et al., 2011

Other Chronic Disease

Anxiety 10.9-13.5%

Depression ~1 in 2 - 4

Close ^

### Generalized anxiety disorder prevalence and comorbidity with depression in coronary heart disease: A meta-analysis

Phillip J Tully, Suzanne M Cosh,

First Published January 8, 2013 | Research Article | [Check for updates](#)

<https://doi.org/10.1177/1359105312467390>

1025 unique citations. Aggregate generalized anxiety disorder prevalence (12 studies,  $N = 3485$ ) was 10.94 per cent (95% confidence interval: 7.8–13.99) and 13.52 per cent (95% confidence interval: 8.39–18.66) employing *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition* criteria (random effects). Lifetime generalized anxiety disorder prevalence was 25.80 per cent (95% confidence interval: 20.84–30.77). In seven

PLoS One. 2016; 11(5): e0156167.

Published online 2016 May 26. doi: [10.1371/journal.pone.0156167](https://doi.org/10.1371/journal.pone.0156167)

PMCID: PMC4881911

PMID: [27228158](https://pubmed.ncbi.nlm.nih.gov/27228158/)

### Base Rates of Depressive Symptoms in Patients with Coronary Heart Disease: An Individual Symptom Analysis

Sebastian Kohlmann,<sup>1,\*</sup> Benjamin Gierk,<sup>1,2</sup> Alexandra M. Murray,<sup>1</sup> Arne Scholl,<sup>1</sup> Marco Lehmann,<sup>1</sup> and Bernd Löwe<sup>1</sup>

- In total, 1337 in- and outpatients with CHD were screened for depressive symptoms with the Patient Health Questionnaire-9 (PHQ-9).
- During the last 14 days, more than half of patients reported a loss of energy (74.9%, 95% Confidence Interval (CI): 70.6–79.2), sleeping problems (69.4%, 95% CI: 64.9–74.0), loss of interest (55.7%, 95% CI: 50.8–60.7). In contrast, psychomotor change (25.6%, 95%CI: 21.3–30.0), feelings of failure (21.9%, 95%CI: 17.7–26.0), suicidal ideations (14.1%, 95%CI: 10.7–17.6) were less frequently reported.

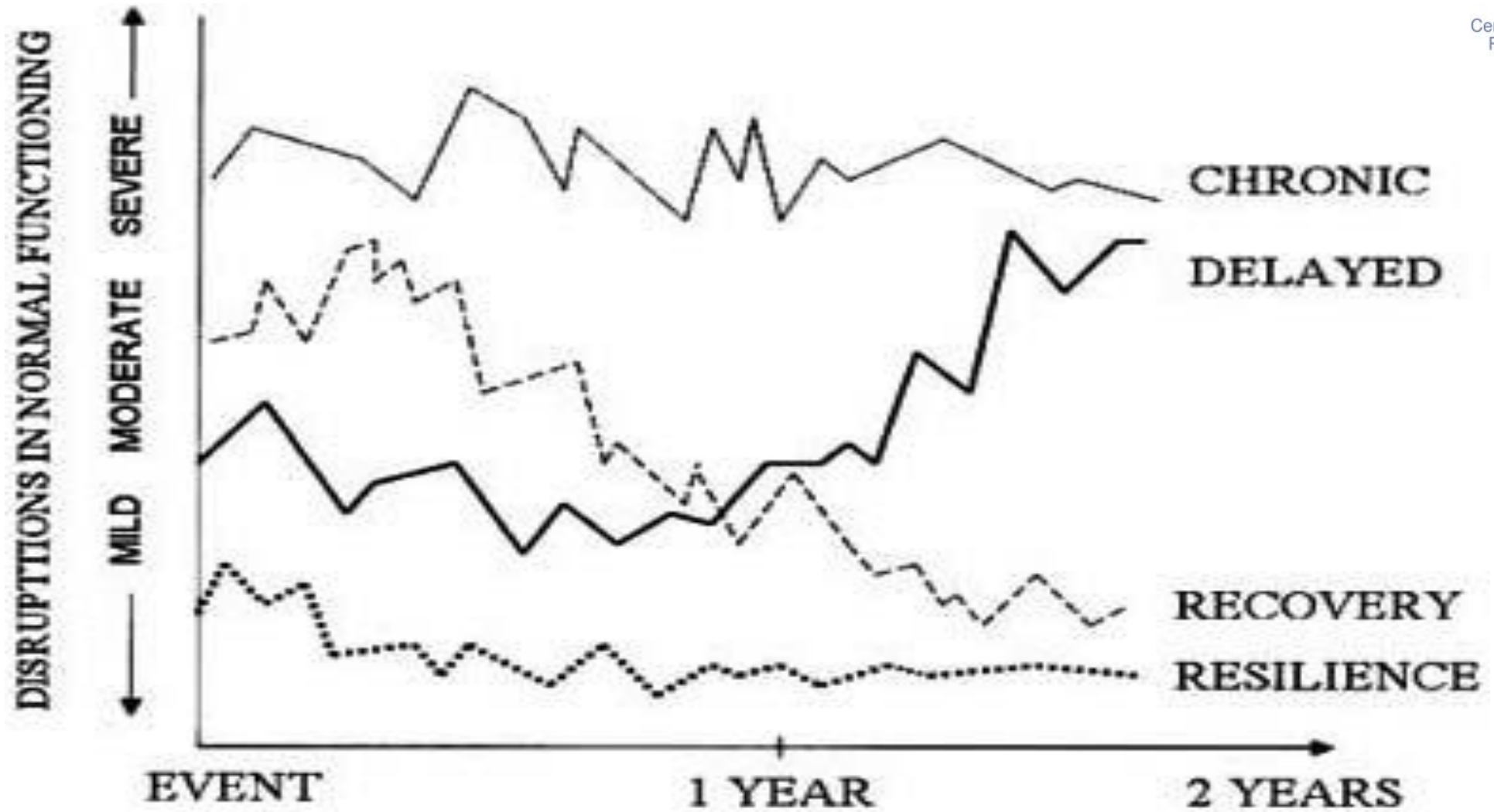


Figure 1. Prototypical Patterns of Disruption in Normal Functioning Across Time Following Interpersonal Loss or Potentially Traumatic Events

From: Bonanno: Am Psychol, Volume 59(1).January 2004.20-28

## Identification and Prediction of Distress Trajectories in the First Year After a Breast Cancer Diagnosis

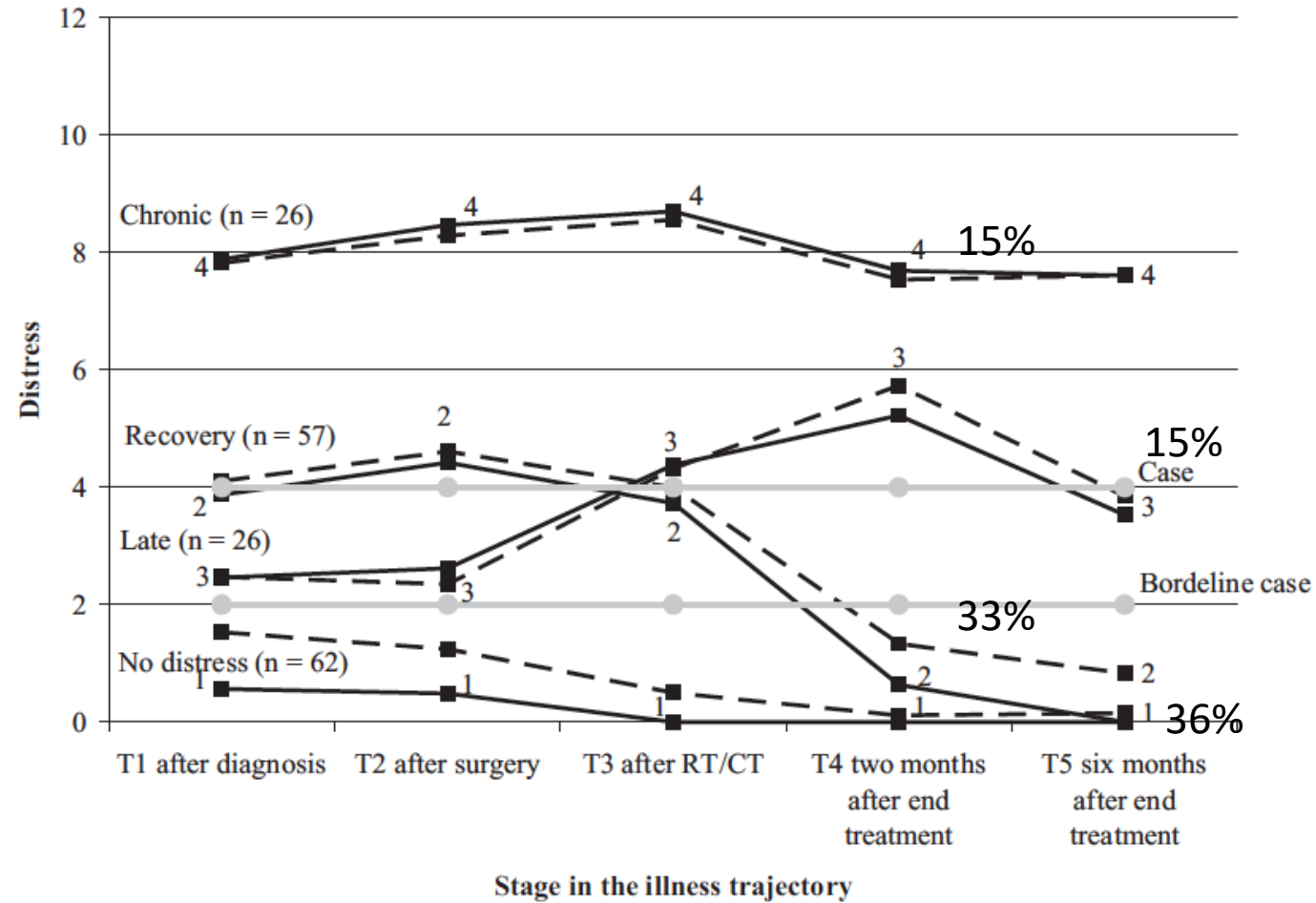
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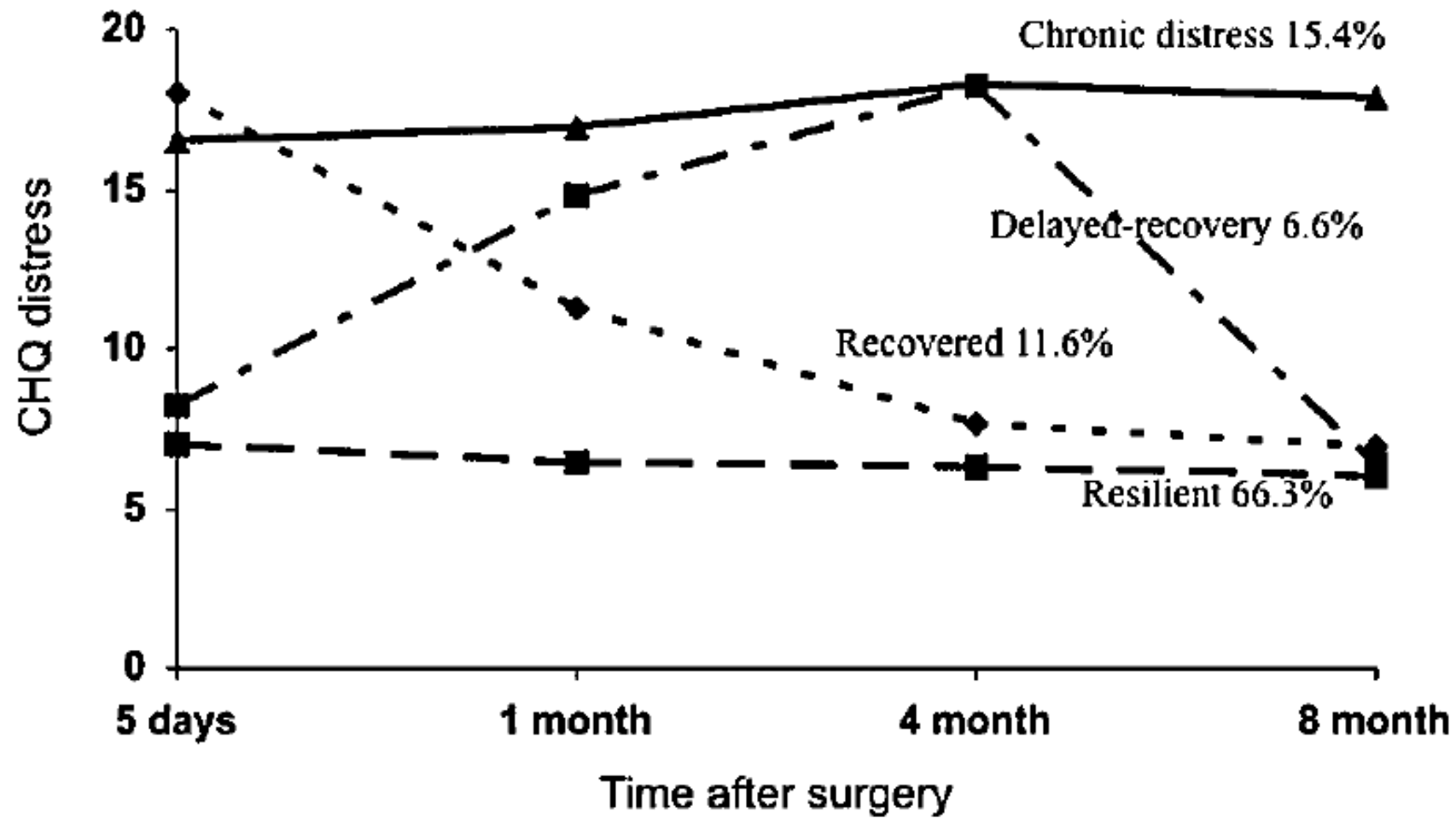
Vicki S. Helgeson  
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University Medical Center Groningen

Robbert Sanderman and Adelita V. Ranchor  
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**Figure 1.** Trajectories of distress following breast cancer surgery

# Serial point prevalence estimates vs. trajectory studies

- "Standard model" : Distress highest around time of ca dx, declining over subsequent year (e.g. Bleiker et al, 2000, Kwak et al, 2013; Lester et al, 2015) – whole sample average.
- Trajectory studies paint different picture (e.g. Helgeson et al 2004; Henselmans et al, 2010; Lam et al 2010, 2012; Rottmann et al 2016)
- Most ca patients (~60%) have low distress; 15-20% have persisting high distress; remainder high ->low, or low-high-low.
- Distress trajectory membership in the 12 months following diagnosis predicting distress status up to 6 years later (Lam et al, 2011) and possibly longer (Brinkman et al, 2013).



# Distress trajectory membership 6- years...

- Distress trajectory membership predicts persistence of distress for at least 6 years post-surgery.



Paper

## Distress trajectories at the first year diagnosis of breast cancer in relation to 6 years survivorship

Wendy W. T. Lam [✉](#), Yee Ting Shing, George A. Bonanno, Anthony D. Mancini,  
Richard Fielding

First published: 2 December 2010 [Full publication history](#)

DOI: 10.1002/pon.1876 [View/save citation](#)



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Volume 21, Issue 1  
January 2012  
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*“Results:* Distress trajectories over the first 8 months post-operatively predicted psychosocial outcomes 6 years later. Women with stable low levels of distress over the first 8 months post-operatively (resilient group) had the best 6-year psychosocial outcomes. **Women who experienced chronic distress had significantly greater longer-term psychological distress, cancer-related distress, and poorer social adjustment in comparison to women in the resilient group. Women in the recovered or delayed-recovery groups were comparable to those in the resilient group, except for concerns about appearance and sexuality, and self-image.”**

Chronic distress persists; transient distress more likely associated with body image and sexuality issues.

# Why does distress persist?

- Unmet supportive-care needs, often in relation to CRRSs, uncertainty, communications




## [Supportive Care in Cancer](#)

March 2014, Volume 22, [Issue 3](#), pp 635–644 | [Cite as](#)

### The evolution of supportive care needs trajectories in women with advanced breast cancer during the 12 months following diagnosis

Authors

[Authors and affiliations](#)

Wendy W. T. Lam , Janice Tsang, Winnie Yeo, Joyce Suen, Wing Ming Ho, Tze Kok Yau, Inda Soong, Ka Yan Wong,

Ava Kwong, Dacita Suen, Wing Kin Sze, Alice W. Y. Ng, Afaf Girgis, Richard Fielding

“With the exception of sexuality needs, **trajectory patterns were predicted by physical symptom distress**. Women in the high-decline group reported greater physical symptom distress.

#### Conclusions

Most Chinese women with advanced breast cancer showed low stable supportive care needs.

**Physical symptom distress predicted high supportive care needs.**

Interventions should focus on optimizing symptom assessment and management.”

# Cancer-related residual symptoms (CRRSs)

- Cancer-related residual symptoms include all symptoms related to the cancer and its treatment, that are present during, and continue after treatment ends.
  - Sometimes called “cancer late-effects”, “residual effects”, or “residual symptoms”,
  - Refers to sensations and bodily changes from
    - cancer,
    - primary treatment (usually surgery),
    - secondary treatment (radiotherapy/chemotherapy),
    - Adjuvant therapies (hormone, targeted, monoclonal)
  - And psychosocial distress - pre-existing and reactive
  - reactive
    - Psychological, social and occupational functional disruption,
    - Distress and,
    - Other Quality of Life decrements

# Why are CRRSs important?

- Disease-related: Metabolic, disruptive, esp. advanced disease:
  - Weight/appetite, energy/fatigue, pain, sleep,
- Primary treatment – usually disfiguring → body image/self-esteem/functional/ social:
  - Impacts identity, self-concept, relationships, abilities (e.g. eating, sexual, excretion), self-efficacy, roles, confidence;
- Secondary treatment (radiotherapy/chemotherapy):
  - skin changes, hair loss, weight gain, fatigue, sleep disruption,
- Adjuvant treatment.
  - peripheral parasthesias; arthralgia; balance disturbance.

# Psychosocial difficulties

- Pre-existing
  - Many cancer patients have coping and stress related problems that pre-date their cancer – cancer adds another demand to an already high demand background.
- Reactive – different elements
  - Existential – Will cancer kill me? Why has this happened to me?
  - Role conflict – job, family, other responsibilities vs. being a patient
  - *Disease and treatment-related interference*
  - Life interruption and re-prioritization
  - Recurrence,
  - Re-normalization
  - Anticipation (fear) of recurrence and loss-related

# What evidence CRRSs are important?

- Earlier studies of Chinese breast cancer patients consistently show symptom burden associated with greater distress over time.



Original Article

## Predicting psychological morbidity in Chinese women after surgery for breast carcinoma

Wendy W. T. Lam Ph.D., Richard Fielding Ph.D. , Ella Y. Y. Ho M.Med.Sci.

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DOI: 10.1002/cncr.20810 [View/save citation](#)

After adjustment, *high physical symptom distress*, baseline psychological morbidity, low optimism, and no chemotherapy independently predicted follow-up CHQ12 scores (adjusted  $R^2 = 0.585$ ).

“Among 430 Chinese women who were approached within 1 week after undergoing surgery for early-stage breast carcinoma (baseline), 405 women (94%) completed measures of self-efficacy and psychological morbidity (the Chinese Health Questionnaire 12-item instrument [CHQ12]).... One-month post-surgery follow-up, CHQ12 scores for 367 of 405 women (91%) were adjusted for background characteristics.

- Physical symptoms “cause” psychological problems

Lagged relationships among sleep disturbance, fatigue, and depressed mood during chemotherapy.

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[Jim, Heather S. L.](#) [Jacobsen, Paul B.](#) [Phillips, Kristin M.](#) [Wenham, Robert M.](#) [Roberts, William](#) [Small, Brent J.](#)

## Citation

Jim, H. S. L., Jacobsen, P. B., Phillips, K. M., Wenham, R. M., Roberts, W., & Small, B. J. (2013). Lagged relationships among sleep disturbance, fatigue, and depressed mood during chemotherapy. *Health Psychology, 32*(7), 768-774.

<http://dx.doi.org/10.1037/a0031322>

Health Psychology

Editor Kenneth E. Freedland, PhD

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“The aim of the current study was to examine lagged changes among daily symptoms during platinum-based chemotherapy. Method: Participants were 78 women with gynecologic cancer (mean age 63 years,  $SD = 11$ ; 91% Caucasian, 97% non-Hispanic). Sleep disturbance was assessed via wrist actigraphy, whereas fatigue and depressed mood were assessed via daily diary in the week after participants’ first chemotherapy infusion. Latent change score models (LCS) were used to examine lagged relationships between symptom pairs. **Results: High levels of sleep disturbance (i.e., minutes awake at night) were associated with earlier subsequent peaks in fatigue, and high levels of fatigue were associated with higher subsequent levels of depressed mood.** Conclusions: These findings suggest that sleep disturbance, fatigue, and depressed mood occur in a cascade pattern during chemotherapy, in which increases in sleep disturbance contribute to fatigue, which, in turn, contributes to depressed mood. Interventions targeting symptoms early in the cascade, such as sleep disturbance, may provide benefits across multiple downstream symptoms.”

Time 1

Time 2

Time 3

Pain/  
Worry/  
Diurnal  
disruption



Sleep  
disturbance



Fatigue



Depressed  
mood



## Fatigue after breast cancer treatment: Biobehavioral predictors of fatigue trajectories.

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Database: PsycARTICLES Journal Article

[Bower, Julienne E.](#) [Wiley, Joshua](#) [Petersen, Laura](#) [Irwin, Michael R.](#) [Cole, Steve W.](#) [Ganz, Patricia A.](#)

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Bower, J. E., Wiley, J., Petersen, L., Irwin, M. R., Cole, S. W., & Ganz, P. A. (2018). Fatigue after breast cancer treatment: Biobehavioral predictors of fatigue trajectories. *Health Psychology, 37*(11), 1025-1034.  
<http://dx.doi.org/10.1037/hea0000652>

Health Psychology

**Editor** Kenneth E. Freedland, PhD

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after primary treatment for early stage breast cancer and at regular follow-ups that occurred up to 6 years after treatment (M = 4.3 years). Growth mixture models were used to characterize fatigue trajectories, and demographic, medical, and biobehavioral risk factors were examined as predictors of trajectory group.

- Results: Five trajectories were identified, characterized as High, Recovery, Late, Low, and Very Low fatigue.
- In multivariate models, depressive symptoms **and childhood adversity** distinguished High and Recovery from other groups...

# 7. In advanced BC, pre-existing difficulties

- ABC, persistent distress and demoralization



PAPER

## Comparing the meanings of living with advanced breast cancer between women resilient to distress and women with persistent distress: a qualitative study

W. W. T. Lam [✉](#), S. W. Yoon, W. K. Sze, A. W. Y. Ng, I. Soong, A. Kwong, D. Suen, J. Tsang, W. Yeo, K. Y. Wong, R. Fielding

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[View issue TOC](#)  
Volume 26, Issue 2  
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### “Results

Women with persistent distress viewed their diagnosis as another blow in life, the illness was global, permeating every aspect of their life. Maladaptive rumination and thought suppression were common responses to illness demands. These women had poor social support. A sense of demoralization stood out in their narratives. In contrast, women with transient/low-stable distress encapsulated the illness, with minimum impacts of their life. They did not evidence dysfunctional repetitive thoughts. Living in a supportive environment, they were able to accept and/or live in the present-moment.”

# Natural Histories of Distress in cancer

- Accumulating evidence suggests different natural histories of cancer-related distress:
  - 1. Initial high distress declining over time: Reaction to initial shock and other issues (financial, role function) associated with a cancer diagnosis.
  - 2. Distress that increases over time: arising from the impact of treatments on function and appearance – symptom related, potentially chronic.
  - 3. Pre-existing distress, overlaid by 1 and 2 above – associated with chronic, high levels of distress, persistent.
  - 4. “Existential” distress, issues regarding meaning, purpose, spirituality, fear of recurrence, financial issues, etc. Arising later in disease trajectory/survivorship.

# Summary

- Most patients were psychologically resilient in response to cancer diagnosis
- Chronic distress
  - Breast cancer 10% to 15%
  - Predictors
    - Poor social support
    - Poor personal resources (e.g. pessimism, low self-esteem, negative intrusive thoughts)
    - Unmanaged physical symptom distress
    - Poor satisfaction with treatment decision making

# Implications



Centre for Psycho-Oncology  
Research and Teaching

- Cancer patients who experienced persistent distress during the acute phase reported the worst longer-term outcomes
- Interventions should be targeted to differentiate those who are at risk of persistent distress during the acute phase of illness trajectory
  - Ensuring optimal communications and decision-making support are essential
  - Assessing symptom distress and optimizing symptom management should be implemented at early post-operative phase
  - Screening patients for poor social and personal resources likely to be more cost-effective if resources are limited.
  - Intervention to match problem type.

# Conclusion

- Distress can both pre-date diagnosis, and persists long after.
- Much distress experienced by cancer patients appears transient and related to unmet needs, particularly poor information giving/distress difficulties...? Self-resolving
- Persistent distress groups may have pre-existing coping inadequacies and/or perceptual distortions.
- Physical symptoms are a major cause of psychological distress as well as directly impacting on quality of life.
- Physical symptoms can cascade making them important targets for interventions: Critically, inadequate pain control and anxious rumination can disturb sleep. These are important intervention targets to prevent psychological distress.
- Subsets of distress with different natural histories exist and inform types, times and duration of interventions.

# Team members

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