CancerSupportSource® Caregiver: Development of a Multidimensional Distress Screening Measure for Family and Informal Cancer Caregivers

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BACKGROUND
Caregiver distress affects the quality of life and health of caregivers as well as the well-being of cancer patients. Supportive care is underutilized by cancer caregivers, in part due to systemic gaps in access and lack of time.

AIMS
We developed and psychometrically evaluated CancerSupportSource®-Caregiver (CSS-CG), part of a web-based distress screening and referral program. The goal of CSS-CG is to identify and respond to unmet caregiver need, enabling caregivers to better navigate care, practice self-care, and support patients.

METHODS
400 caregivers enrolled in Cancer Support Community’s online Cancer Experience Registry® survey. Caregivers provided sociodemographic and caregiving history information, rated their level of concern for 33 CSS-CG items on a 5-point Likert scale, and reported their level of concern for 33 CSS-CG items on a 5-point Likert scale.

Participants were randomly split into two samples for exploratory factor analysis (N=250), and confirmatory factor analysis and evaluation of psychometric properties of the final scale (N=150). Scale reduction was informed by item endorsement, iterative EFA and a hierarchical EFA, and item reduction (N=250), and confirmatory factor analysis and evaluation of psychometric properties of the final scale (N=150).

SCALE REDUCTION AND FINAL MEASURE
Factors and items

EMOTIONAL WELL-BEING

- Feeling frightened or afraid
- Feeling sad or depressed
- Feeling lonely or isolated
- Worrying about the future and what lies ahead
- Changes in disruptions in work, school, or home life

PATIENT WELL-BEING

- Changes in the patient’s mood or behavior
- Changes in the patient’s memory or thinking
- The patient’s pain or physical discomfort
- The patient’s eating and nutrition

PHYSICAL WELL-BEING

- Coordinating medical care for the patient
- Providing transportation to treatment and appointments
- Providing physical or medical care to the patient
- Making treatment decisions

FINANCES

- Managing household income and medical bills
- Managing household income and medical bills

HEALTHY LIFESTYLE

- Exercising and being physically active
- Keeping up with your health care needs
- Eating well
- Getting enough sleep

TOBACCO & SUBSTANCE USE

- Using alcohol or other substance use
- Using tobacco or other substance use

EVALUATION OF PSYCHOMETRIC PROPERTIES

CONCLUSIONS AND IMPLICATIONS
- CancerSupportSource-Caregiver (CSS-CG) is a psychometrically robust measure of caregiver distress.
- In its full program implementation, CSS-CG can facilitate distress screening, referral, and follow-up to rapidly assess caregivers’ unmet needs and enhance well-being.
- Future implementation goals include understanding how to best engage caregivers in diverse settings, including oncology practices and ambulatory sites.

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REFERENCES


