

Identification of Pain, Emotional Distress, and Suicidality among Breast Cancer Patients: Gaps Between Patient Reports and Medical Charts

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ABSTRACT

Background: Healthcare providers frequently fail to identify mental health problems in cancer patients. In this preliminary study, we examined differences between patients' self-report and documentation in medical charts in identification of pain, emotional distress and suicidality among women with breast cancer during the first months following diagnosis.

Methods: A convenience sample of women with breast cancer (N=105) completed self-report questionnaires and their medical charts were reviewed by research assistants.

Results: While a majority of patients reported suffering from some pain it was noted in less than fifth of the medical charts. Similarly, approximately a third of the patients self-reported mood and/or anxiety disorder, yet it was noted in only 2.8% of medical charts. Finally, six patients self-reported suicidal risk, but none of the medical charts included any report about patients' suicidality.

Conclusions: Providers should be educated about the importance and the rationale behind the need for assessment of emotional distress and trained to correctly identify it.

Breast cancer is the most frequently diagnosed cancer in women worldwide. During the diagnostic phase of the illness trajectory, women with breast cancer are at higher risk for developing emotional distress and chronic pain (1). Breast cancer patients are also at an increased risk for suicidality (2), though completed suicides remain relatively rare (2%). Importantly, suicidal ideations are more prevalent among cancer patients, particularly during early stages of the disease (2).

Accurate identification of mental health distress and pain in cancer patients is essential for treatment planning and has consequences to the overall quality of life of the patient and their family as well as for improving treatment compliance and potentially increasing survival time (3). Reliance on patient self-reports to identify emotional distress is widely used, yet, it has a number of limitations including bias related to insight and motivation (4).

Depending on healthcare providers' assessment of mental health, disorders can also be subject to limited reliability due to the lack of comprehensiveness of standard clinical interviewing practices (5) and a bias toward under-identification. Healthcare providers frequently fail to recognize the presence of mental health distress and suicidality (6), leaving emotional distress and particularly suicidal ideation to be often undetected and untreated (3).

In the current preliminary study, we examined whether there were differences between patients' self-report and documentation in medical charts in identification of emotional distress, persistent pain and suicidality. We collected information from women with breast cancer in the first few months following diagnosis and compared

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their self-reported needs to the information noted in their medical charts by the healthcare providers.

METHODS

SETTING AND SAMPLE

We conducted the study in oncology units in three large academic health centers across Israel. A convenience sample of 105 women with breast cancer were recruited by their treating oncologist. Participants were within eight months of diagnosis. Exclusion criteria included absence of metastasis.

Participants' ages ranged from 27 to 83 years old ($M = 54.58$ $SD = 13.4$). A majority of the patients were born in Israel (64.2%), were Jewish (89.4%), and were married or living with a partner (74.5%). Approximately half of the patients were employed (52.4%), and a majority had an average and/or above average income (67%). Approximately, a third of patients received chemotherapy (33.3%, $n=35$), 16% ($n=17$) received radiation, 46% ($n=48$) received both treatments and a small number received neither treatment (4.7%, $n=5$). Approximately 9% of the sample has been diagnosed with a similar or different cancer in the past ($n=9$), and over 70% of the patients reported having a close relative who was also diagnosed with cancer ($n=77$, 73.3%).

MEASURES

Anxiety and Depression Scale (HADS7))). This 14-item self-report measure contains two subscales (Anxiety, Depression) and a global emotional distress score. Each item is rated on a 4-point scale. Previous research conducted among cancer patients in acute care to identify optimal cutoff scores for the HADS documented that total score ≥ 13 is optimal to detect caseness (presence of mood and/or anxiety disorders) (Cronbach's α HADS total=.88).

The Suicide Behavior Questionnaire - Revised (SBQ-R) (8). A self-report instrument that includes 4 items evaluating past suicide attempts, the frequency of suicide ideation in the past year, threats of suicide and self-reported likelihood of suicide attempt. Total score ranges from 3 to 18. Previous research recommended using cutoff score ≥ 7 to detect suicidality in non-suicidal samples (8) (Cronbach's $\alpha = .68$).

Pain severity (9). Using an 11-point scale anchored at 0 (no pain) and 10 (as intense as you can imagine), participants rate their current pain and the occurrences of the average least and worst pain they felt over the pre-

ceding two weeks. Cronbach's α was calculated including all four items (Cronbach's $\alpha = .91$).

PROCEDURE

The study was approved by the Institutional Ethics Committees in all participating hospitals, and data collection was in compliance with human subject protocols. After participants were recruited to the study by their treating oncologist and signed an informed consent form, they completed self-report questionnaires in their native language (Hebrew or Arabic). Two trained coders reviewed the patients' medical charts to collect relevant documented clinical information. A third coder independently recoded a random sample of the charts (14%; $n=15$) to establish interrater reliability which was high (interclass correlation for single measure=.96).

RESULTS

We compared the identification of pain, emotional distress, and suicidality as reported by the patient and identified by the healthcare provider and recorded in the patient's medical chart. Regarding pain severity, in less than a fifth of the medical charts there was a documentation of any pain ($n=15$, 14.28%), while an overwhelming majority of patients reported suffering from some pain ($n=79$, 75.5%). Similarly, while only in a small minority of patients' medical charts the healthcare provider recorded a presence of mood and/or anxiety disorder ($n=3$, 2.85%), approximately a third of the patients ($n=36$; 35%) received a total score on the HADS that indicated a presence of mood and/or anxiety disorder (≥ 13). Regarding suicidality, none of the medical charts included any report about patients' suicidality. In contrast, based on the patients' self-report (Suicide Behavior Questionnaire; $M=3.77$ $SD=1.65$) six patients (6%) received a total score on the SBQ that indicated presence of a suicidal risk (≥ 7).

DISCUSSION

Similar to previous studies our findings show that in most cases healthcare providers fail to document mental health co-morbidities in the patients' medical charts. Presumably, the low-recorded pain, mood and anxiety disorders and suicidality in patients' medical charts reflect under-diagnosis and under-identification (6).

Timely and accurate identification of mental health co-morbidity among breast cancer patients is paramount.

It is the first step in addressing the severe problem of treatment gap.

Although professional standards in oncology care emphasize a holistic approach to care that includes systematic screening for emotional distress among breast cancer patients (10), and although reliable and valid measures exist (e.g., Distress Thermometer), the problem of under-identification of emotional distress in oncology care persists, especially around lack of systematic assessment for suicidality. As our data show, none of the patients who self-reported suicidal concerns had any information about suicidality in their medical charts.

Recent research suggests that lack of training and time constraint are common structural barriers to identifying and managing emotional distress in oncology settings (6). Healthcare providers and particularly oncologists may have difficulty in differentiating between mental health distress and symptoms of the disease and tend to perceive distress to be a normative part of having cancer (6). Healthcare providers also report fear of asking about suicidality, and lack of coping resources to deal with suicidal patients (6).

Our sample could be subject to selection bias as it included a convenience sample of women who agreed to participate in a study, potentially representing those who are more open to discuss mental health concerns. It is also possible that healthcare providers assess the patients' mental health status but do not record it in the medical chart. Third, due to the relatively small sample size we could not conduct analyses to identify factors predictive of greater congruence between patients' self-report and documentation in medical charts.

Providers should be educated about the importance and the rationale behind the need for identification of emotional distress and trained to identify and manage it including providing referrals to specialized care when needed.

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