

Depressive symptoms, fear of emotional expression, and less favorable attitudes toward palliative care

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Many patients with cancer are reluctant to consider palliative care services due to fears and misconceptions regarding the goals of palliative care.¹ Depressive symptoms also predict less preferential attitudes toward palliative care.² Individuals often respond to stressful events including serious illness and depression with defensiveness, withdrawal, and avoidance of otherwise supportive relationships, particularly if they fear that others will judge their emotional reactions. Thus, patients experiencing depressive symptoms may be reluctant to consider palliative care because they fear the consequences of accepting their vulnerable emotions and expressing them to others—potentially because they have been previously criticized for expressing their emotions.³

Depression is a heterogeneous disorder. Loss of interest, low mood, difficulty concentrating, and pessimistic beliefs may make it difficult for some patients to accurately assess the potential benefits of palliative care, while physiological symptoms such as fatigue, sleep, and psychomotor disturbances may create barriers to adjusting routines. Patients who inhibit their emotions tend to experience higher levels of distress and, for reasons poorly understood, tend to have poorer cancer outcomes.⁴ Patients with depression may adopt a decision-making style that prioritizes the short-term relief of avoiding emotional distress over the possible long-term benefits of addressing their palliative care needs.² Another possibility is that fears of expressing emotion could also lead these patients to avoid upsetting healthcare consultations, and procedures such as palliative care that may enhance emotional and physical well-being, if not subtle increases in survival.^{5,6}

This study investigated the potential role that fear of emotional expression may play in shaping preferences for palliative care. Understanding these fears could potentially help to enhance palliative care utilization in at-risk and acutely distressed patients. A mediation model was computed to test the hypothesis that the association of depression with less preferential attitudes toward palliative care would be mediated by fears of emotional expression.

1 | METHODS

1.1 | Participants

This study has been described previously (Hoerger et al., 2017) (Data citation). Adult patients (age ≥ 18) receiving oncology care with a current or previous cancer diagnosis were invited to participate in the study using the National Institutes of Health's ResearchMatch tool (See the supplemental appendix). In total, 633 participants were recruited and provided valid data. Of these, 598 cases were analyzed; 35 had received palliative care previously and were excluded. The median age was 63 years (Range = 27 to 93), 57.2% were male, and 73.9% were married. The sample was predominantly White and non-Latino/a (93.3%). The most common cancers were prostate (51.2%), breast (19.7%), skin (12.2%), lung (11.0%), and colon/rectal (9.5%) cancers. Other cancer diagnoses accounted for 13.0% of the sample. The median time since diagnosis was 4 years (IQR: 1.5 to 7.0 years).

Participants most frequently indicated that they no longer showed evidence of disease (58.5%), followed by early stage/localized disease (26.6%), and distant metastases (16.9%).

1.2 | Measures

The patient-reported outcome measurement information system (PROMIS⁷) Depression Short-Forms assessed depression. Participants indicated if they felt “Helpless,” “Worthless,” “Hopeless,” and “Depressed” in the past seven days using a 1 (Never) to 5 (Always) scale ($\alpha = .91$).

Fear of Emotional Expression was assessed using a single item, “Did you feel afraid of expressing your feelings?”. Participants rated the item based on their experience over the prior seven days using a 1 (Never) to 5 (Always) scale. The de novo item was developed to maximize face validity and brevity to minimize participant burden. Preliminary evidence of convergent and divergent validity was demonstrated through a large correlation with depressive symptoms, and small correlations with extant variables such as pain and treatment side effects ($r = .26$, and $r = .20$).

The Palliative Care Attitudes Scale⁸ assessed participant attitudes toward palliative care. The measure described the nature of palliative care consultations and asked participants to indicate their attitude toward palliative care on 14 items assessing perceived stress, beliefs about the utility of palliative care, and willingness to pursue palliative care consultation (total score $\alpha = .87$).

Analysis. Analyses were conducted using SPSS version 26. Mediation analyses were computed using the PROCESS package.⁹ Models were adjusted for plausible confounders including age, gender, cancer type, metastatic disease, education, and time since diagnosis. Gender was included given gender differences in rates of depression and emotional expression.

2 | RESULTS

Approximately 24.7% endorsed moderate to severe depressive symptoms. Depressive symptoms were strongly associated with greater fear of emotional expression ($r = .60$, $P < .001$; See Supplemental Table S1) and less favorable attitudes toward palliative care ($r = -.20$, $P < .001$). Fear of emotional expression was also associated with less favorable attitudes toward palliative care ($r = -.20$, $P < .001$).

Mediation results are presented in Figure 1 (See Supplemental Table S2 for all regression coefficients). The model accounted for 38% of the variance in fear of emotional expression and 10% of the variance in palliative care preferences. Time since diagnosis ($B = .001$, $SE = .0004$, $P < .003$) and female gender ($B = 4.49$, $SE = 2.10$, $P = .029$) were associated with more favorable attitudes toward palliative care. Cancer history, age, education, and metastatic disease were not significant predictors. The total effect, ($B = -.65$ $SE = .13$ 95% $CI = -.9129$ to $-.3916$), direct effect ($B = -.44$ $SE = .16$ 95% $CI = -.7658$ to $-.1275$), and indirect effect ($B = -.21$ $SE = .10$ 95%

Key Points

- Patients with depression may fear expressing emotions.
- Patients with depression may also be reluctant to utilize palliative care.
- Fear of emotional expression partially explains the link between depression and palliative care preference.
- Acknowledging fears of emotional expression could enhance supportive care discussions.

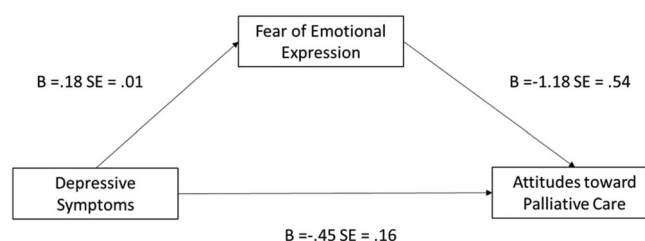


FIGURE 1 Mediation model path diagram

$CI = -.4023$ to $-.0075$) of depression were all statistically significant. The ratio of the indirect to total effect indicated that approximately one-third ($(B = -.21 \text{ (Indirect)}) / (B = -.65 \text{ (Total)}) = .32$) of the association between depression, and palliative care preferences was explained by fear of emotional expression.

3 | DISCUSSION

Participants with higher levels of depressive symptoms had less favorable attitudes toward palliative care services. Palliative care consultations often include some assessment of emotional well-being. Patients who fear expressing their emotions may anticipate that these conversations will be aversive and therefore best avoided.⁶

Although inhibition of emotion may partially explain less preferential attitudes toward palliative care among patients with depression, the remaining direct effect suggests that other depression-related processes influence preferences and decision-making regarding palliative care. Pessimistic outlooks may lead to doubts about potential benefits of palliative care. Another possibility is that patients may not consider delayed benefits of supportive care when acutely distressed.²

The findings are qualified by the study strengths and weaknesses. A large geographically-diverse sample of patients with cancer histories participated in the study. Weaknesses include a cross-sectional design that limits causal interpretations, and a racially homogeneous sample. Moreover, the primary outcome was attitudes toward palliative care, and there exist additional drivers of utilization, including referral norms and access issues. Although participants were excluded from

analysis if they had received a palliative care consultation, the study did not assess if patients had previously been offered palliative care consultation. Lastly, the study relied on a brief unvalidated measure of fears of emotional expression. Future research should include comprehensive measures of emotional regulation and expression.

These findings may have implications for engaging reluctant patients in supportive care services. Depression and emotional inhibition unfold in a complex interpersonal context.³ Patients often look to their oncologist for support and use conversations to calibrate expectations about their illness and adjustment. Given that emotional contagion may occur between patients and their oncology clinicians,¹⁰ patients may be less inclined to explore emotional concerns when their own fears intersect with provider reluctance to elicit and respond to difficult emotions. Inversely, some reticent patients may benefit from conversations and patient education that elicit and normalize expressions of difficult emotions.

Further research is needed to determine whether tailoring patient education on palliative care can enhance utilization among depressed patients. It is possible that patient educational materials that target psychological flexibility could enhance interest in palliative care. To the extent that these processes are not amenable to change, patients who tend to cope with emotional repression and inhibition may respond better to discussions of concrete behavioral strategies (eg, behavioral activation, low-impact exercise) that rely less on emotional exploration and expression.

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DATA AVAILABILITY STATEMENT

Data supporting the study findings are available upon reasonable request.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of this article.

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