

Cancer caregiver perception of symptom severity change

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Background

Advanced cancer brings a cascade of difficult decisions and challenges for patients and their family caregivers. Among the challenges are unpleasant symptoms related to the disease and treatment. Symptom assessment during cancer treatment is challenging because symptoms often escalate between clinic visits. Patients and caregivers must recall the symptom experience over the previous weeks during clinic visits. It is unknown whether perception of change in the severity of symptoms can be accurately recalled by caregivers. The **purpose** of this paper is to describe caregiver-reported perception of change in symptom severity in relation to actual reported symptom severity.

Methods

- Participants were 191 family caregivers of patients receiving hospice care for advanced cancer randomly assigned to intervention or usual care
- All caregivers placed daily calls to an automated system, Symptom Care at Home (SCH) that assessed severity for patient pain, anxiety, and depressed mood and caregiver mood and anxiety (0-10 scale)
- If reported severity differed by 2 or less points from the previous call, caregivers were asked whether the symptom was less, the same, or more severe than the previous call
- Participants assigned to the intervention group received automated care coaching and hospice nurse alerts for poorly controlled symptoms
- Correlations between reported change and perceived change were calculated using linear mixed effects models

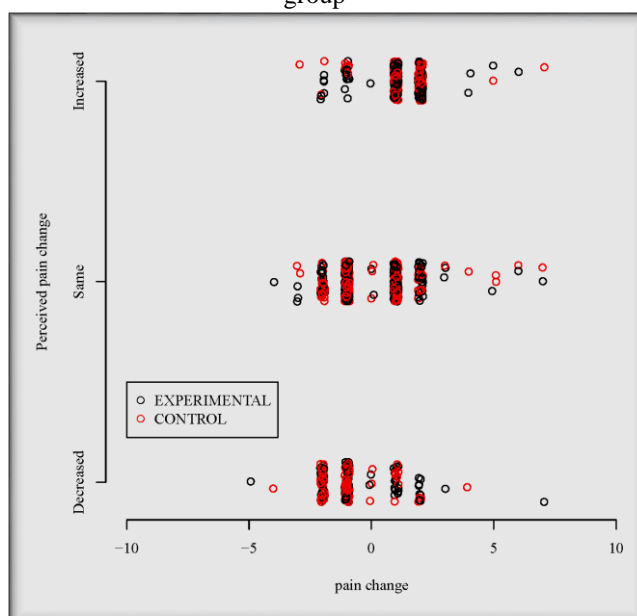
Results

- Reported change and perceived change in patient pain ($R = 0.45$), caregiver mood ($R = 0.44$), and caregiver anxiety ($R = 0.40$) were moderately correlated
- Reported change and perceived change in patient anxiety ($R = 0.29$) and patient depressed mood ($R = 0.36$) were weakly correlated
- There was a significant interaction between intervention versus control group and reported change in pain severity on perceived change in pain severity ($p < 0.0001$)

Table 1. Sample Characteristics

Characteristic	Mean (SD)
Patient Age (in years)	73 (13)
Caregiver Age (in years)	59 (14)
Characteristic	n (%)
Patient Gender	
Male	87 (45.8%)
Female	103 (54.2%)
Caregiver Gender	
Male	53 (27.9%)
Female	137 (72.1%)
Caregiver Relationship	
Child	68 (35.8%)
Spouse/Partner	102 (54.2%)
Other	21 (10.0%)

Figure 1. Scatterplot of caregiver perceived change in patient pain severity and caregiver reported change in patient pain severity by intervention versus control group



Discussion

The strength of the correlation between perception and reported change varied by symptom, as perception of change in patient psychosocial symptoms was weakly correlated to reported change and perception of change in patient pain and caregiver mood and anxiety were moderately correlated to reported change. Clinicians may consider evaluating both reported change in symptoms and perception of change. Further research is needed to determine whether perception of change varies as reported symptom severity varies. Clinicians may be aware that caregivers may benefit from intensified monitoring and coaching as the intervention enhanced caregiver perception of patient pain.

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