

# Family Caregivers-Key Members of the Oncology Careforce

## Technology-aided support beyond the walls of the cancer facility

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# Family Members Are the Invisible Members of the Oncology Careforce

Caregiving extracts a toll



# Family Caregiver Experience of Moderate-to-Severe Health Concerns

Family Caregivers during Home Hospice Care

Concern	4 or > on 10 point scale	%
<b>Fatigue</b>		<b>84</b>
<b>Interference with normal activities</b>		<b>81</b>
<b>Anxiety</b>		<b>78</b>
<b>Disturbed sleep</b>		<b>78</b>
<b>Depressed mood</b>		<b>73</b>



# Symptom Care at Home (SCH)

NCI funding PO1CA138317

Automated Family Caregiver Support during Home Hospice Care  
Randomized Controlled Trial, N=332

- ▶ Automated daily monitoring of 11 common patient symptoms and 5 indicators of caregiver wellbeing- reported by the caregiver and includes presence, severity (1-10), drill-down
- ▶ Automated algorithm-based, just-in-time, tailored family caregiver coaching based on reported patient symptoms and intensity paired with coaching to improve caregiver wellbeing.
- ▶ Automated provider alerts (hospice nurse) based on preset thresholds (stepped intervention)



# Significant Benefit for Patients

## Supporting Family Caregivers to be Effective

- ▶ Overall significantly less symptom severity for patients than usual hospice care;  $p=.03$
- ▶ Moderate-to-severe patient symptom days reduced by 38% in SCH group compared to usual hospice care;  $p<.001$



# Significant Benefit for Family Caregivers

- ▶ 51% reduction in the number of moderate-to-severe symptom days for family caregivers (caregiver fatigue, disturbed sleep, anxiety, depressed mood, interference with normal activities) compared to usual hospice care families ( $p < .001$ )
- ▶ In SCH (but not UC), caregiver symptom reduction mediated a reduction in patient symptoms ( $p = .027$ ) thus **supporting the caregiver's health translates to improved patient symptom outcomes** as well; both are benefited
- ▶ 6 months after the patient's death, SCH spouses showed better bereavement outcomes than UC spouses ( $p < .007$ )

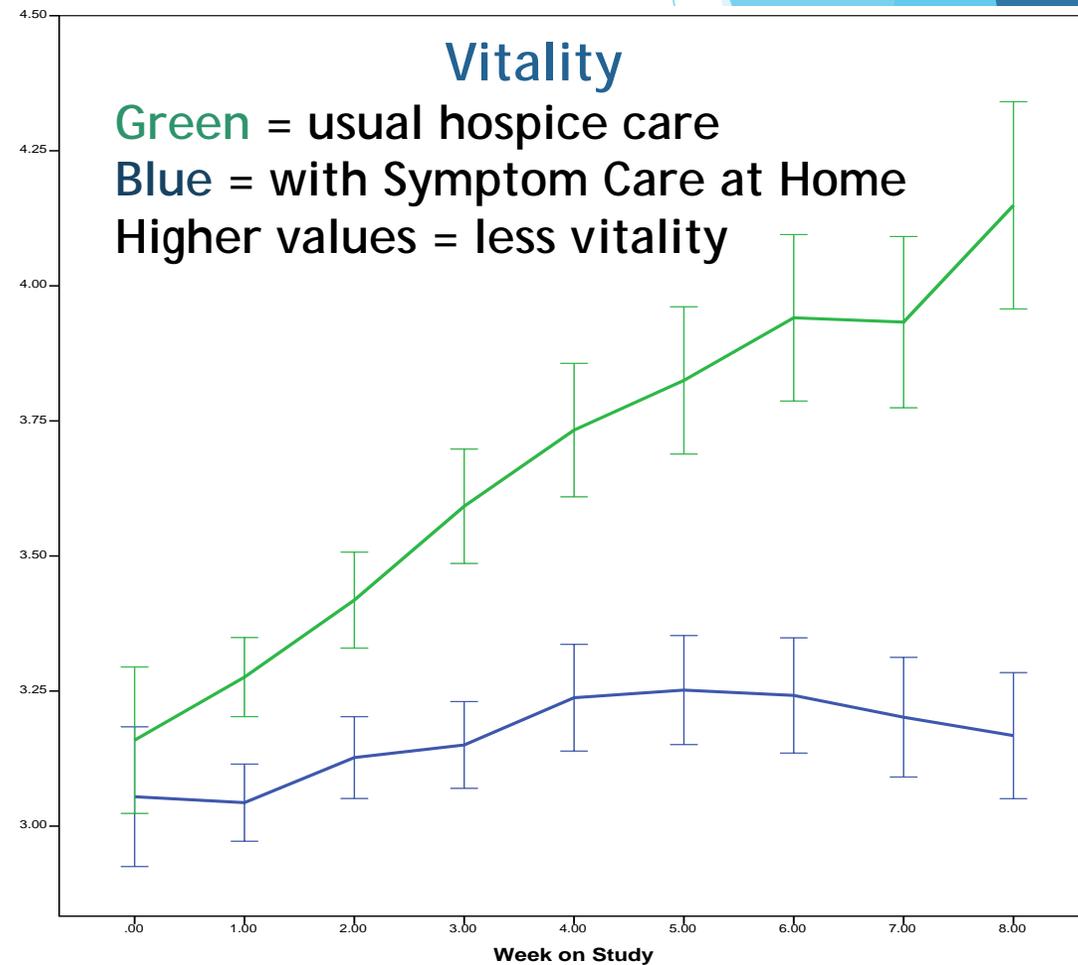
# Supporting Family Caregivers to be Resilient

## Caregiver vitality maintained during caregiving

Lower fatigue, better sleep, and less activity disruption ( $p < .001$ ;  $d = .71$ )

## Caregiver mood

Less disruption in mood anxiety and depressed mood ( $p = .002$ ,  $d = .51$ )



# Caregiver Post-Intervention Interviews

- ▶ **I did my calls at the end of the day and it was a release of sorts for me...the time I spent alone at night to reflect on mom's day and how she did.**
- ▶ **Good outlet/input for me-pointing out I wasn't alone and she was not really unusual.**
- ▶ **It gave me a sense of confidence that what I was seeing and feeling was 'normal'.**
- ▶ **It helped calm me when I was having a bad day.**

- ▶ **Being able to anonymously tell someone what is going on.**
- ▶ **It felt like someone else was listening to what I had to say. Another person on the team.**
- ▶ **It made me realize I was forgetting who he had been. I was just seeing him as a sick person- that was so helpful so I could change.**
- ▶ **It got me through the hardest time in my life.**

# Support When and Where Patients and Family Caregivers Need It Made Possible with Technology

- ▶ Automated algorithm-based coaching to aid family caregiving of the patient and also support caregiver well-being- providing tailored, just in time support
- ▶ Provider alert system for concerns that exceed preset thresholds- providing a stepped intervention to conserve provider time but notifies provider when intensified patient and family support is needed

