



## Enhancing Well-being and Improved Symptom Outcomes during Advanced Cancer through Family Caregiver Support

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## Symptom Care at Home (SCH) Study

- The aim of this study was to evaluate whether the addition of an automated, telephone-based remote symptom monitoring and coaching system for family caregivers that utilized IVR (interactive voice response) technology, improves symptom outcomes for both patients and family caregivers in the home hospice setting.




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## Background

- Monitoring and intensifying care as symptoms rapidly change during advanced cancer is challenging in the home setting.
- Hospice care recognizes the family as the unit of care thus monitoring and providing support to family caregivers is a key focus for intervention.
- Automated telehealth approaches can provide an additional 'just in time support' for families and triage symptom concerns that require clinician attention.
- Use of technology to monitor and support family caregivers at home may provide added value to current hospice care services.




### Symptom Care at Home (SCH)

- Randomized controlled trial to test the efficacy of SCH in the home hospice setting as compared to usual hospice care (UHC)
- SCH is an automated, telephone-based remote monitoring system using IVR (interactive voice response) technology
- Daily automated monitoring of 11 patient and 5 caregiver symptoms (presence/severity over the past 24 hours, 0-10 scale)
  - patient symptom severity as reported by the caregiver
  - caregiver symptoms: fatigue, disturbed sleep, anxiety, depressed mood and interference with normal activity
- UHC = daily calls for data collection (non-actionable)
- SCH = daily calls to monitor symptoms with automated coaching and hospice nurse alerts based on the specific symptom patterns reported.



### SCH Intervention First Component: Caregiver Coaching Tailored to Reports

- Automated symptom coaching tailored to reported symptom pattern (for family caregiver care of the patient and family caregiver self-care)
  - Introduction to caregiving first 3 calls
  - Coaching based on symptom severity & number of days reported without relief - 3 levels
  - Offered patient care strategies and self-care strategies based on palliative care guidelines
  - Symptoms normalized and context provided
  - The caregiver receives coaching on issues that they should address with the hospice team.



### SCH Intervention Second Component: Alerts Clinicians about Poorly Controlled Symptoms

- Automated symptom alerts of symptoms at preset thresholds - moderate to severe levels (4-10) plus trend alerts
  - Sent to the family's hospice nurse immediately at the end of call
  - Hospice nurses had mobile access to the alert website - iPad or hospice mobile system
  - Website displayed last 24 hour patient and caregiver symptom report plus graph(s) of symptoms over time for since hospice admission so trends could be seen
  - Nurses logged that alert data was seen and their action plan (monitor, call, visit) - not told what to do



### Demographics

- 12 U.S. Hospices in 4 states
  - (Illinois, Massachusetts, Oregon, and Utah)
- 121 Hospice nurses
- 298 Cancer patient/family caregivers dyads (144 SCH, 154 UHC)
  - Patient mean age 72; 52% female
  - Family caregiver mean age 59; 69% female, 53% were spouse/partners, 37% adult child, 10% other relative



### Family Caregiver Call Adherence and Call Length

Daily Call Adherence

- Mean days on study prior to patient's death= 45 days
- Call adherence: SCH 73%; UHC 66% of daily calls

Average Call Length

- SCH intervention group call length: 11 minutes
- UHC group call length (symptom reporting only): 9 minutes

Call volumes

- 8,090 total calls
- 5,416 calls (67%) triggered hospice nurse alert thresholds for poorly controlled symptoms




### Poorly Controlled Patient Symptoms were common

Prevalence of Symptoms Reported at Moderate or Severe Levels  
(4-10 on 10 point scale)

Patient symptom	%
Fatigue	90
Pain	80
Poor appetite	71
Anxiety	63
Confusion	63
Depressed mood	62
Constipation or diarrhea	60
Trouble sleeping	57
Difficulty breathing	37
Nausea or vomiting	33
Urinary problems	32




### Symptom Care at Home Patient Benefit

- For all symptoms combined, **significantly less symptom severity for SCH patients** than usual hospice care; p< .001; mixed effects modeling
- Moderate to severe patient **symptom days were 38% less** frequent in the SCH group compared to usual hospice care; p<.001; negative binomial regression





### Significant reduction in severity for 10 of the 11 patient symptoms for SCH

Patient symptom	% Reduction in moderate-severe days over UHC	
	days over UHC	p
Fatigue	20	<.001
Pain	33	<.001
Poor appetite	43	<.001
Anxiety	47	<.001
Confusion	50	<.001
Depressed mood	41	<.001
Constipation or diarrhea	43	<.001
Trouble sleeping	42	<.001
Difficulty breathing	64	<.001
Nausea or vomiting	0	NS
Urinary problems	44	<.001




### Rapid Onset and Maintenance of Intervention Benefit for SCH Patients over Usual Hospice Care $p < .04$

Kaplan-Meier Curve  
1<sup>st</sup> Reporting Day of No Moderate-Severe Patient Symptoms

On average, first mild symptom day for SCH group came two weeks before usual hospice care

Legend:  
 - SCH Intervention  
 - Usual Care  
 - SCH Intervention - censored  
 - Usual Care - censored

Number of Days until First Moderate/Severe Day

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### Symptom Care at Home Family Caregivers

- 51% reduction in the overall number of days with moderate-to-severe symptoms for family caregivers compared to usual hospice care;  $p < .001$
- Caregiver mood (anxiety and depressed mood) was significantly better for SCH than usual hospice care;  $p = .003$

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### SCH Intervention Protective Effect on Caregiver Vitality

Higher score equates with loss of vitality

Legend:  
 - UHC  
 - SCH

- SCH Caregivers had lower fatigue, better sleep, and less normal activity disruption than usual hospice care,  $p < .001$
- SCH family caregivers were able to maintain vitality while caregiving whereas usual hospice caregivers lose vitality during caregiving

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### Supporting Family Caregiver's Health Translates to Improved Symptom Outcomes for Patients As Well

- In SCH (but not UHC), family caregiver symptom reduction mediated a reduction in patient symptoms,  $p = .027$
- Focusing on caregiver health also benefits patient well-being

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### Sustained Benefit for SCH Spouse Caregivers Better Bereavement Adjustment 6 Months Post-death

- Duration of effect of the SCH intervention continued into bereavement even though the intervention ended at patient death.
- SCH spouse/partner caregivers showed better bereavement adjustment outcomes at 6 months post-death than UHC spouses/partner caregivers (p=.005)




### 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 was going on made it so much easier for me.




- It made me realize I was forgetting who he had been. I was just seeing him as a sick person- that was so helpful to be reminded so I could change.
- It felt like someone else was listening to what I had to say. It provided another person on the team.
- It got me through the hardest time in my life.




### Symptom Care at Home

- Provides an added layer of support in hospice and home palliative care.
- Helps bridge geographic disparities in care- i.e. rural place of residence
- Can be easily adapted into any language/dialect
- Targets the changing symptoms and needs of both patient and caregiver
- Optimized through technology to minimize clinician time, yet provide frequent assessment and caregiver coaching support while alerting the hospice or palliative care team when needed
- Remote monitoring and automated coaching offers added benefit as a component of hospice and home palliative care.



