Speaking from the Heart: The Changing Goals of Heart Failure Patients in the Last Years of Life

Sandra E. Schellinger, RN, MSN, NP-C, Allina Health, Minnesota | July 24, 2017 Care Preferences at End of Life
I have no relevant commercial relationships to disclose.
What matters most?
LifeCourse Overview
Key Components of LifeCourse

1. Care Guide
2. Whole Person
3. What Matters
4. Family & Community

LifeCourse Impact

**Better Care**
- better *quality of life*
- improved patient *care experience*
- more patients with *advance care plans*

**Lower Utilization**
- 40% fewer ICU stays
- 23% fewer inpatient days

**MEDIAN HOSPICE LENGTH OF STAY**
- LifeCourse: **33 days**
- Usual care: **14 days**

8:1 return on investment

www.lifecoursemn.org
|---------------|---------------|---------------|
| **Life Course Symposium:** Design, Results, and Implementation of a Whole Person Intervention for Late Life Care  
Presenter: Paige Bingham  
[paige.bingham@allina.com](mailto:paige.bingham@allina.com) | **Palliative Care for Older Adults**  
LifeCourse Paper: Effect of a Person-Centered Intervention on Patient Experience With Care in Serious Chronic Illness  
Time: 2:00 PM - 3:30 PM  
Presenter: Nathan Shippee  
[nshippee@umn.edu](mailto:nshippee@umn.edu) | **Quality of Life and Well-Being: International Perspectives**  
LifeCourse Paper: Improving Quality of Life for Late Life Patients: Key Findings From LifeCourse Intervention  
Time: 8:00 AM - 9:30 AM  
Presenter: Tetyana Shippee  
[tshippee@umn.edu](mailto:tshippee@umn.edu) |
| **Care Preferences at End of Life**  
LifeCourse Paper: Speaking From the Heart: The Changing Goals of Heart Failure Patients in the Last Years of Life  
Time: 4:00 PM - 5:30 PM  
Presenter: Sandy Schellinger  
[sandra.schellinger@allina.com](mailto:sandra.schellinger@allina.com) | **Unique Perspectives in Understanding End of Life Care Experiences**  
LifeCourse Paper: Health Care Utilization Outcomes for Patients Enrolled in a Late Life Care Intervention  
Time: 2:00 PM - 3:30 PM  
Presenter: Anne Betzner  
[anne.betzner@allina.com](mailto:anne.betzner@allina.com) |
Descriptive Analysis of Self-Defined Goals and End of Life Preferences

• How do individual preferences and priorities change over the advanced heart failure trajectory prior to death?

• What are possible points along the disease trajectory that can help clinicians to proactively discuss goals of care and provide support for patients and families?

• 30 advanced heart failure patients who died and received LifeCourse support greater than 12 months.
Advanced Heart Failure

Intervention
## Core Questions and Assessments

<table>
<thead>
<tr>
<th>Goals</th>
<th>Visit #1</th>
<th>Visit #2</th>
<th>Visit #3</th>
<th>Visit #4</th>
<th>Visit #5</th>
<th>Visit #6</th>
<th>Ongoing</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Review What Matters Most and Goals</td>
<td></td>
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</tr>
<tr>
<td>Question Sets</td>
<td>Physical</td>
<td>Cultural</td>
<td>Social</td>
<td>Spiritual</td>
<td>Financial &amp; Legal</td>
<td>Care at the End of Life</td>
<td>Revisit/Update Question Sets</td>
</tr>
<tr>
<td></td>
<td>Family</td>
<td>Psychological</td>
<td>Cultural</td>
<td>Revisit/Update Question Sets</td>
<td>Legacy</td>
<td>Social</td>
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</tr>
<tr>
<td></td>
<td>Ethical</td>
<td>Financial &amp; Legal</td>
<td></td>
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<tr>
<td>Assessment Tools</td>
<td>ESAS</td>
<td>PPS</td>
<td>Who’s At Your Table activity</td>
<td>ESAS</td>
<td>PPS</td>
<td></td>
<td>Revisit Assessment Tools</td>
</tr>
</tbody>
</table>

**ACP**

- **Validation**
- **Reconciliation**
- **Clarification**

NQF, 2013, Smith, 2002
Care Guide Goals of Care Conversation

Step 1: Elicit Goals and What Matters Most

Step 2: Determine Willingness to Take Action

Step 3: Support Patients with Goals

Step 4: Revisit and Revise Goals

Step 5: Global Statement

Advance Care Planning Conversations

Validation

Reconciliation

Clarification

Documentation

• Visit Notes

• Patient Story
  • What I want my health care team to know about me.
  • What matters most to me
  • Goals
  • Summary of the whole person

• Advance Care Planning
Methods and Results
Data Collection and Coding

• Qualitative coding of goals by whole person domains and advance care planning preferences by categories.

• Key data points from the goals flowsheet and centralized advance care planning documentation were mapped over time.
Total Goals Distribution over 32 months for 30 Advance Heart Failure Patients (n=287 goals)

*Other domains: End of life care 5%, Ethical 4%, Psychological 3%, Legacy/Bereavement 1%, Spiritual 1%
Percentage of Active Goals Per Domain by 6-month Time Period, Measuring Back From Death

- Physical
- Social
- Other*
- Housing
- Family/Caregiver
- Financial/Legal

<table>
<thead>
<tr>
<th>Time Period</th>
<th>Goals</th>
</tr>
</thead>
<tbody>
<tr>
<td>25-30 mo (n=7 pts.)</td>
<td>4 Goals</td>
</tr>
<tr>
<td>19-24 mo (n=14 pts.)</td>
<td>10 Goals</td>
</tr>
<tr>
<td>13-18 mo (n=29 pts.)</td>
<td>7 Goals</td>
</tr>
<tr>
<td>7-12 mo (n=30 pts.)</td>
<td>9 Goals</td>
</tr>
<tr>
<td>Death-6 mo (n=30 pts.)</td>
<td>9 Goals</td>
</tr>
</tbody>
</table>

Appendix
"I want to stay in my house as long as possible."

I want to:

- Explore relevant issues around safety and care needs.

**Housing**

- Continue to be active as able.
- Continue to be as active as possible and plan for future needs.

**Multiple:** Housing, Physical

- Plan to have a family meeting.

**Multiple:** Housing, Family/Caregiver

- This goal is still important to me. [Under the new documentation definitions, this goal is being changed to What Matters Most]
### Longitudinal Description of Medical Goals

<table>
<thead>
<tr>
<th>Domain</th>
<th>Plan description</th>
<th>Months Before Death</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical</td>
<td>&quot;The cancer is back...I do not want to treat it.&quot;</td>
<td>30</td>
</tr>
<tr>
<td></td>
<td>1. Consulting oncologist...understand current state...options...doing nothing.</td>
<td>24</td>
</tr>
<tr>
<td></td>
<td>2. Wishes to learn...treatments, benefits, burdens...decision to treat.</td>
<td>18</td>
</tr>
<tr>
<td></td>
<td>3. More tests...progression cancer...decide palliative treatment... hospice.</td>
<td>12</td>
</tr>
<tr>
<td>Multiple:</td>
<td></td>
<td>6</td>
</tr>
<tr>
<td>Physical, End of Life Care</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

"The cancer is back...I do not want to treat it."
Longitudinal Description of Non-Medical Goals

<table>
<thead>
<tr>
<th>Domain</th>
<th>Plan description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Multiple:</td>
<td>&quot;I want to leave some money for my children and grandchildren&quot;</td>
</tr>
<tr>
<td>Financial/Legal, Family/ Caregiver, Physical</td>
<td>1. Get info...protect assets.</td>
</tr>
<tr>
<td></td>
<td>2. Meet...financial planner.</td>
</tr>
<tr>
<td></td>
<td>5. Continue to be frugal.</td>
</tr>
<tr>
<td></td>
<td>6. Decide if priority given care needs.</td>
</tr>
</tbody>
</table>

Months Before Death

30 24 18 12 6
Advance Directive Documentation

- Health Care Directive (HCD)
- Physician Orders for Life Sustaining Treatments (POLST)

ACP baseline:
- 40% HCD
- 3% No Advance Directive Document
- 3% Treatment Guideline

ACP death:
- 43% HCD
- 10% POLST
- 33% HCD

Health Care Directive (HCD), Physician Orders for Life Sustaining Treatments (POLST)
Goals of Care Preference

Goals of Care Preference changed 6.3 months before death.

- **27% Full Treatment**
- **13% Limited Intervention**
- **60% No Goals of Care Discussions Assume Full Treatment**

Goals of Care Death:
- **23% Full Treatment**
- **13% Limited Intervention**
- **50% Comfort Care**
- **13%**
Cardiopulmonary Resuscitations (CPR), Do Not Resuscitate (DNR)

- 40% CPR
- 17% CPR Unless
- 20% DNR
- 23% No Code Status Discussion Assume Full Code

Code Status Changed on average 11.7 months before death

- 23% CPR
- 20% CPR Unless
- 53% DNR
- 3% Code Status Death
Onset of self-defined goals and change in life sustaining treatment preferences

Median Length of Stay in LifeCourse, 19.5 (12-31) mos.
N=30 Advanced Heart failure Patients

*Other includes self-defined goals attributed to the care at the end of life, ethical, legacy/bereavement, psychological, and spiritual domains
Conclusions

• Serious illness goals of care conversations could start 2 years prior to death.

• We have an opportunity to support medical and nonmedical goals.

• Ongoing discussions about goals of care may allow for integration of patient values, goals and preferences into care decisions.
Appendix
Serious Illness Goals in the Medical Record

Patient Story

What Matters Most to me at this time:

“I want to stay in my house as long as possible.”
Serious Illness Goals in the Medical Record

Patient has stated the following goals and plans:

Focus 1: “Never give up hope of staying in my home.”
Focus 2: “I want to get off or take less pain medications.”
Focus 3: “I want to have more energy and stamina.”
Focus 4: “I always hope to make a trip to visit friends and family, here and in Europe.”
Focus 5: “Protect my assets, get my affairs in order to leave some money for my family.”
Focus 6: “Discuss my health with family.”
Focus 7: “I don’t want to go back to the hospital unless I have severe pain.”
Focus 8: “The cancer is back. I do not want to treat it.”
Advance Care Planning Documentation

Health Care Agent(s)
• Primary and alternate Health Care Agent
• Decision Maker

Advance Care Plan Documents:
• Health Care Directive, POLST, Treatment guidelines

Specific Treatment Preferences:
• Code Status: [CPR; CPR unless DNR/ Do Not Attempt Resuscitation - Allow a Natural Death]
• Goals of Treatment: [i Comfort Care; ii. Limited Interventions and treat reversible conditions; Full Treatment]


References


THANK YOU!