Bridging the Culture Gap: Improving Palliative Care through Patient Navigation

Regina Fink, PhD, APRN, CHPN, FAAN
Associate Professor
School of Medicine & College of Nursing

University of Colorado Anschutz Medical Campus

iPallCARE™
preparing palliative care professionals
Faculty Disclosure

• I have no financial relationships to disclose
• I have no conflicts of interest to disclose
• I will not promote any commercial products or services during my presentation
Objectives

• Describe content of lay patient navigator visits with seriously ill Latino patients and their family caregivers

• Review a model for lay patient navigation

• Determine the impact of a lay patient navigator to improve advance care planning in the community and palliative care outcomes
I watch fields, as nature
Invites pastoral bliss...
Irides and oaks glow
Imbued with morn’s fresh soil;
Igniting rural charm
In mind’s eye. O hometown
Illumines peace ... earth’s gift!

©nette onclaud
APOYO CON CARIÑO: Improving Palliative Care to Latinos using a Patient Navigator Intervention

**American Cancer Society 2012-2016 (RSG12-182-01)**
- Randomized Controlled Trial
- 223 Latino adults with advanced (Stage III or IV) cancer
- Rural and urban sites in Colorado
- Improved advance care planning (ACP) documentation and QOL

**NIH National Institute of Nursing Research 2016-2020 (R01-NR016467-01)**
- Randomized Controlled Trial
- 240 Latino adults with advanced non-cancer illness & family caregivers
- Rural and urban sites in Colorado
- Outcomes: Improved ACP, improved pain/symptom management, decreased hospitalizations and costs, increased hospice utilization

Fischer, Fink et al., J NCCN, 2017
Fischer, Fink et al., JAMA Oncology, 2018
Our Apoyo con Cariño Team
Apoyo *Oncology* Study Site Partners

Denver Health Medical Center
University of Colorado Cancer Center
St Joseph’s Comprehensive Cancer Center
San Luis Valley Regional Medical Center
Rocky Mountain Cancer Center in Pueblo
Western Slope
- Shaw Regional Cancer Center – Vail Health
- Calaway - Young Cancer Center at Valley View Hospital
- Aspen Valley Hospital
- Grand River Hospital in Rifle
- St. Mary’s in Grand Junction
Apoyo Advanced Medical Illness Study Site Partners

- Denver Health Medical Center
- University of Colorado Health
  - Metro
  - North (Fort Collins, Greeley, Loveland)
  - South
- Centura Health
- Kaiser
- Western Slope
  - Colorado Mountain Medical
  - Mountain Family Health
  - Grand River Health
Patient Navigator Intervention

• 5 home visits to deliver the intervention
• Culturally tailored discussions
  • Advance care planning
  • Pain and symptom management
  • Resources and hospice
Core Latino Values

- Familia - family
- Confianza - trust
- Personalismo - relationship
- Espiritulismo - spirituality
- Fatalismo - fatalism
Examples of Written Materials

Advance directive
Page of pain brochure
Hospice brochure
Hospicio?
I would not want to just send my loved one away to some place.
Navigators work WITH patients, families, and communities to empower them to overcome barriers in the health care system and enjoy better health and health care.
Accrual for Apoyo con Cariño

318 referred

284 agreed to meet for consenting visit

223 Enrolled and Randomized

111 control

90 completed 3 month

1 too ill to complete
8 dropped out
12 deaths

112 intervention

87 completed 3 month

4 too ill to complete
7 dropped out
14 deaths

25 ineligible
9 unable to contact

61 refused participation

111 control

112 intervention

12 deaths

87 completed 3 month

8 dropped out
14 deaths
### Demographics Baseline

<table>
<thead>
<tr>
<th>Category</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean age in years</td>
<td>58.1 ± 14</td>
</tr>
<tr>
<td>Female gender</td>
<td>55.6% (124)</td>
</tr>
<tr>
<td>Spanish speaking</td>
<td>47.5% (106)</td>
</tr>
<tr>
<td>US born</td>
<td>54.3% (121)</td>
</tr>
<tr>
<td>Married</td>
<td>55.6% (124)</td>
</tr>
<tr>
<td>Currently employed</td>
<td>11.8% (26)</td>
</tr>
<tr>
<td>Annual income &lt; $15,000</td>
<td>53.6% (118)</td>
</tr>
<tr>
<td>Less than high school education</td>
<td>50.2% (112)</td>
</tr>
</tbody>
</table>
Results: Advance Care Planning

- Spoke with family about future health care preferences: 55% (Control) vs. 84% (Intervention) \( p<0.0001 \)
- Spoke with health care provider about future health care decisions: 35% (Control) vs. 60% (Intervention) \( p=0.001 \)
- Completed advance directive on the chart: 33% (Control) vs. 69% (Intervention) \( p<0.0001 \)
Results: Quality Of Life

<table>
<thead>
<tr>
<th>Category</th>
<th>Control</th>
<th>Intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>MQOL total</td>
<td>7.1</td>
<td>7.2</td>
</tr>
<tr>
<td>Emotional</td>
<td>6.8</td>
<td>7.2</td>
</tr>
<tr>
<td>Existential</td>
<td>7.9</td>
<td>8.1</td>
</tr>
<tr>
<td>Physical</td>
<td>5.8</td>
<td>6.86</td>
</tr>
<tr>
<td>Support</td>
<td>8.6</td>
<td>8.8</td>
</tr>
</tbody>
</table>

p = 0.007
Results: Hospice and EOL Utilization-Process

Would recommend hospice for loved one in the future: 65% (p < 0.001) vs. 88% (对照组 vs. 干预组)
Would use hospice themselves in the future: 66% (p < 0.001) vs. 88% (对照组 vs. 干预组)

Used Hospice: 78% (对照组) vs. 83% (干预组) (n = 120)
Conclusions/Implications

Contamination (culture change), especially at rural/mountain sites with 1-2 oncologists and highly engaged clinic staff, may explain these negative results.

Patient navigator intervention effective for increasing ACP and improving overall symptom control.

No demonstrated effect on pain severity, pain interference, or on hospice utilization.
PN Orientation and Enrichment Activities

- ELNEC Training
- Patient Navigator training
- Motivational interviewing
- Weekly team meetings
- Yearly retreats
- Access to the team
Field Notes: Qualitative Analysis Methods

• 4 Patient Navigators made 499 visits to 112 patients
• Codes were established *a priori* to identify different ways the navigator might help patients/families.
• Atlas.Ti
• Additional codes established during multiple readings
• Common themes to expand our understanding of patient/family palliative care needs
Palliative Care Patient Navigator Compass
“Before the doctor would consider her as a medical trial candidate, the patient had to work on accountability. At a recent visit, the doctor stepped out and the patient reveals to me that she hasn’t been taking the medicine for the cancer. Instead she’s been taking some Canadian medicine recommended by some people; she doesn’t want me to tell the doctor. I replied that I would do as she wished but that would be a terrible mistake not to give that information to the doctor. I held her hand and told her that if she was my sister I would ‘make’ her tell the truth, but only she could decide. When the doctor came back, she tells me that it’s ok, that we can tell him what’s been going on.”
Support

“My patient was sent home today, nothing more can be done for him. They said ‘take him home and make him comfortable.’ His wife was broken and snuck outside to call me. She asked me to pop in to check up on the patient; she did not want him to know that she called me. I will try and stop by on Friday evening...”
Awareness

“We covered the hospice booklet in depth today. The patient seemed very interested in hospice as he did not know such a program existed. He asked where the closest hospice house would be for him.”
“Patient was exhausted; had company all weekend. A community person that came to visit and stayed all morning, told stories about family who had cancer that had died. It was depressing; the patient wanted her to leave. We talked about how to approach this without feeling rude or guilty. A few ideas we came up with:

- ‘My doctor says I should get all the rest I can before I begin treatment and short visit are fine,’
- ‘I’m very tired and you may visit another time,’
- ‘I need to rest now, I want to go to sleep, thank you for the visit, and close her eyes.’

This was actually fun for both of us to role play.”
“Patient had left side pain on the chest, including the breast, under the arm, rib cage, and shoulder blade. She said it was sore like a muscle ache, severe; like a muscle strain on the 10 point scale a level 9 today; that was why she was lying down when I arrived. She would like her pain to be about a level 2. What makes it worse is bending down or over. It is brought on by lots of physical activity which she has not done. She had used a salve all over and was lying down with a hot rice bag on her back and had taken ½ a tablet of Hydrocodone-acetaminophen 5-325mg; started today. She explained that she is very sensitive to pain medication especially Vicodin and tramadol, then she said, ‘well any pain medication.’ She had problems with severe side effects during her last go round of cancer in 1994. She said she uses, aciete de Arrayan, aspercream, hem muscle rub, arnica rub.”
“He told me about receiving a form from Social Services. He does not read very well and has little education. He recanted how the woman at the office yelled at him and told him to complete the form in Spanish. The form was in English and he could not fill it out. He came home totally humiliated with his tail between his legs.”
Access

“On a previous home visit, I emailed an updated worksheet to Sense of Security to assist my patient to access financial support. My patient welcomed me with a letter that said she had been awarded $470 to help pay rent every month until May 2016! She signed the award in front of me, we put it in an envelope, and I took it to the mailbox.”
Rapport

“As I walked away he had a smile on his face and he waved at me and said looking forward to seeing you in 2 weeks. Thanks for all the ideas on how to deal with my emotions. I said you were the one who thought of them all, not me. We both giggled.”
Conclusion, Sustainability, Future Directions

• Lay patient navigator model can impact ACP and provide palliative care support and education to patients/families.

• Incorporating this model in palliative care work with other cultures has a chance to improve palliative care access to other disparate populations.

• We are currently trialing this model in Latinos with advanced medical illness and persons with dementia and family caregivers
Rural Outreach
Community-Based ACP Conversations using Patient Navigation

- 2017-2018
- Bilingual, one-hour group sessions
- Rural, northeastern CO and Western Slope
  - Churches, community centers, libraries, schools, businesses, LTC, clinics, seniors centers, metro districts
- Poster OR PowerPoint, Frequently Asked Questions, AD, goal setting worksheets

Funded by Colorado Health Foundation
Who attended? What did we learn?

• 74 sessions; 1034 participants
• 49% sessions were co-facilitated with an APRN or MD
• 69% female; 38% ethnically diverse
• Post session ACP-4 (47% response rate)
  • 29% planned on naming a decision-maker in the next 6 months; 21% in the next 30 days
  • 26% ready to talk about future healthcare decisions with decision-maker in the next 6 months; 22% in the next 30 days
  • 31% ready to talk to their provider about healthcare preferences in the next 6 months; 14% in the next 30 days
  • 31% ready to complete an AD in the next 6 months; 22% in the next 30 days.
• 98% reporting the session was the right length of time.
Rural Palliative Care Needs Assessment

40% response rate; 192 hospitals; N=374

When asked about palliative care...

- Only 46% of respondents personally wished to learn more about palliative care.
- YET... 80% thought their clinical staff would like to learn more about palliative care.
- Palliative care is integrated into the care plan for seriously ill patients (1.61)
- HCPs are able to recognize the active dying process (2.23)
- Staff is comfortable knowing what to do for the dying patient (2.01)

0=Never, 1=Sometimes, 2=Frequently, 3=Always
Which of the following palliative care services are present in your hospital?
What would you like to learn?

• General PC education
  • Correct basic misconceptions with staff and patients

• Pain management
  • Prescribing and dispensing
  • Nonpharm approaches
  • Alternatives to IV administration

• Communication strategies
  • Delivering bad news, bereavement, end of life, acceptance, ethics

• Care management
  • Service coordination, team, setting standards, writing orders

• Business plan/management
  • How to implement a service in a small hospital, reimbursement, liability
Bridging the gap in palliative care and consultation

**Primary Palliative Care**
- All providers
- Basic PC

**Secondary Palliative Care**
- Palliative Care Community Specialists
- Specialty PC and consultation

**Tertiary Palliative Care**
- Academic Medical Centers
- Complex PC cases
Easing Physical Symptoms
Easing Pain
Easing Suffering
Easing Psychological, Spiritual, Social Distress
Capstone

Palliative Care

Direct access: http://bit.ly/2C5K3mu
Palliative Care Community Specialist

Specialty trained to provide high quality palliative care consultation to patients and families.

Fills a niche:
- Rural, urban, and suburban/community high need areas
- Embed palliative care
- Cost effective
One Program: Two Options

Interprofessional Palliative Care Certificate (IPPC)

12 semester credit hours
4 courses ~ 9 months

Interprofessional Master of Science in Palliative Care (MSPC)
(Includes Capstone project)

36 semester credit hours
12 courses ~ 2 - 7 years

Core Competencies

Palliative Care Community Specialist

Illustrates mastery in the following areas:

- Communication skills
- Expert symptom management skills (pain & non-pain)
- Ethics, advocacy and legal aspects of care
- Spiritual, religious and existential aspects of care
- Psychological, social and cultural aspects of care
- Palliative care integration/systems
- Palliative care educator
Interprofessional Team

Nurses
Pharmacists
Physicians
Physician Assistants
Psychologists
Social Work
Spiritual Care
Ethicists
Humanities
Communications Experts
Questions?