Developing El Concilio:
A Culturally-Tailored Patient and Family Advisory Council for Spanish-Speaking Patients

November 5, 2014
City of Hope is located in Duarte, California
• National Cancer Institute-designated
  Comprehensive Cancer Center
• Founding member National Comprehensive
  Cancer Network

An independent biomedical research, treatment and education institution, we are a leader in the fight to conquer cancer, diabetes, HIV/AIDS and other life-threatening diseases.

Our medical services include hematology and hematopoietic cell transplantation (HCT), medical oncology, surgery, radiation oncology, pediatrics, and endocrinology.
Department of Supportive Care Medicine

Child Life
Clinical Social Work
Pain & Palliative Medicine
Patient Navigation
Psychology & Psychiatry
Spiritual Care
Patient, Family & Community Education
School Program

Biller Resource Center
Caregiver Programs
Positive Image
SupportScreen
Department of Supportive Care Medicine
Background

• Immigrants often:
  – Struggle with language difficulties
  – Lack information
  – Say that health professionals do not understand them

• Immigrants with cancer have been shown to have:
  – Poorer health outcomes
  – Lower survival rates
  – More side effects
  – Poorer quality of life
  – Greater distress

All of the above may adversely affect their psychological well-being. Therefore, tailoring their involvement in decision-making is critical factor in facilitating the gold standard in patient-centered care.

Why a Spanish Advisory Council?

• As patient populations become increasingly diverse, healthcare organizations are demonstrating increased commitment to providing patient-centered care to vulnerable populations (Wynia and Matiasek, 2006).

• Hispanics comprise nearly 20% of the patient population at City of Hope.

• The Spanish-Speaking Patient and Family Advisory Council allows us to link with the community to:
  1. Enhance patient/healthcare team communication
  2. Enhance patient education and safety
  3. Increase awareness and utilization of supportive resources
Getting Started

• Acquired departmental support via Request for Proposal (RFP) process
  – Staff protected time
  – Administrative support
  – Resources: marketing materials, food funds, incentives

• Created a multi-disciplinary team
  – An integrated team of staff from various areas of the institution: social workers, navigator, nursing research, patient resource coordinator, patient health education, and publication staff

• Resulted in what has become a 3-phase process:
  – Phase I Development
  – Phase II Sustainability
  – Phase III Visibility & Utilization
Phase I

“To create an advisory council that will give voice and empower Spanish-speaking patients and caregivers to enhance educational and supportive programs for patients and caregivers at the City of Hope. The council will bridge the language and cultural gap between Spanish-speaking patients and caregivers and the healthcare team and institution.”

<table>
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<tr>
<th>Opportunity</th>
<th>Goals to Meet the Opportunity</th>
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<tr>
<td><strong>Phase I: Development</strong></td>
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| To create a Spanish-speaking, PFAC to inform and pilot linguistically and culturally appropriate educational and supportive care programs for Spanish-speaking patients/caregivers | 1) Marketing and recruitment  
2) Interview process  
3) Council member selection  
4) Council member orientation  
5) Evaluation |
Marketing & Recruitment

- Recruited Spanish-speaking adult patients and their families/caregivers who ranged in:
  - gender
  - age (18 and older)
  - diagnosis (at varying stages of treatment, except newly diagnosed)

- Developed marketing materials for the implementation and launch of our recruitment plan

- Recruitment sources
  - Spanish Look Good Feel Better
  - Spanish Yoga Class
  - Spanish Web site Focus Group
  - BRC Anniversary Celebration – Spanish Programs Booth
  - DSCM Leadership Meetings
  - Health Care Team Members (RN, NP, PA, CSW, etc.)

*An application was included in the recruitment materials with a contact number for questions.*
Interview Process and Member Selection

• Screening and Interviews
  ◦ Solicitation of Health Care Team input
  ◦ Initial telephone screening
  ◦ Face-face interviews

• The Applicants
  ◦ Total of 19
  ◦ 14 interviewed (5 deselected at telephone screening)
  ◦ 5 not selected due to coping or commitment issues

• Nine Concilio members selected
  ◦ 5 patients, 4 caregivers
  ◦ Ages 21 to 56
  ◦ 8 females and 1 male

• Celebratory Mixer
  ◦ Meet and greet for El Concilio members to meet each other
  ◦ Introduced El Concilio to the Department of Supportive Care Medicine
New Member Orientation

• El Concilio members participated in a half-day orientation on March 9, 2012

• Training Agenda:
  – Provision of Council Member Manual
  – COH’s Mission, Programs and Services
  – Corporate Compliance (HIPAA) and Safety (with certified interpreter)
  – Member Expectations & Role of the Council
  – Overview of Rules, Guidelines and Bylaws of the Council
  – Effective Communication
  – Cultural Considerations
  – Bingo Activity (interactive evaluation method)
  – Confidentiality Agreement
  – Program Evaluation
Phase II

“The Spanish-Speaking Patient and Family Advisory Council Task Force is committed to the sustainability and success of El Concilio. We are dedicated to the mentoring and training of its members to firmly establish the council as a vehicle for advocacy, collaboration, and linkage to the Department of Supportive Care Medicine and the institution, at large. This relationship will serve to empower our Spanish-speaking patients, families, and caregivers to actively inform and enhance programs and services at City of Hope.”

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<td><strong>Phase II: Sustainability</strong></td>
<td>1) Mission statement</td>
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<td>Develop a protocol for self-governance and establish a structure for continued</td>
<td>2) Election of a co-chair</td>
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<td>linkage and collaboration with the Department of Supportive Care Medicine and the</td>
<td>3) Member term-limits</td>
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<td>larger institution</td>
<td>4) Collaboration projects</td>
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El Concilio’s Mission Statement

“La misión de El Concilio es de transformar la experiencia y servicios para la comunidad hispana de City of Hope. El Concilio colabora con Miembros del Departamento de Cuidados de Apoyo (Department of Supportive Care Medicine) y con la institución para aportar y educar acerca de la cultura hispana, incorporando elementos esenciales en la provisión de cuidado de salud y apoyo para ofrecer la mejor calidad de vida a cada paciente y sus familiares.

“El Concilio’s mission is to transform the experience and services for the Hispanic community at City of Hope. In collaboration with the Department of Supportive Care Medicine and the institution, El Concilio will contribute and provide education about Hispanic culture, to provide key elements in the provision of healthcare services and support, with the aim of providing the highest quality of life to each patient and their families”.

City of Hope
Accomplishments

• Mission Statement
• Election of a member co-chair
• Revision of by-laws
  ▪ Member guidelines as they pertain to attendance (attend at least 9 of 12 meetings)
  ▪ Maximum council size limited to 12 members
  ▪ Staggered term limits (1 yr, 2 yr, 3 yr service)
Collaboration Projects

- New Patient & Family Orientation in Spanish
- Campus map in Spanish
- Buttons that identify El Concilio members
- Buttons that identify Spanish-speaking COH volunteers
# Phase III Vision

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<td><strong>Phase III: Visibility &amp; Utilization</strong>&lt;br&gt;To increase El Concilio’s visibility within the institution to further develop collaborative relationships</td>
<td><strong>2013-2014 Phase III Sustainability &amp; Visibility</strong>&lt;br&gt;• Solidify key partnerships with the institution&lt;br&gt;• Expand member education/training&lt;br&gt;• Council expansion&lt;br&gt;• Administrative support&lt;br&gt;• Sustainable Program Infrastructure</td>
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Timely Opportunity!

• City of Hope launches Latino Enterprise initiative in 2013

• Human Resources via Diversity and Inclusion Council appoints Glenn Llopis as consultant to El Concilio
  – Revamp of mission statement and creation of logo/value proposition/tagline
  – Official institutional endorsement at Hispanic Pipeline in the Healthcare and Biomedical Fields summit (Dec. 2, 2013)
  – Featured stories in the Healthy Hispanic Living online magazine
El Concilio’s Mission Statement

Improve the overall patient-family experience for Spanish speaking Hispanics at City of Hope through education, translation, information and easy navigation of resources and services to foster high-trust relationships and save lives.

El Concilio Tagline: Inform – Educate – Connect
Value Proposition

INFORM:
El Concilio is a patient-family advisory group that is committed to providing the tools and resources to help City of Hope’s Spanish-language patients make better decisions by being better informed about their healthcare.

EDUCATE:
El Concilio provides a positive, trustworthy patient experience delivered in a safe, consultative environment that is personalized, engaging, and welcoming which encourages an ongoing educational dialogue.

CONNECT:
El Concilio is committed to embracing the importance of Hispanic cultural values to most effectively translate and communicate to patients and their families.
El Concilio Desired Outcomes

• Earn trust from the patient and his/her family

• Increase engagement and a more positive medical treatment experience

• Patients and their families share the positive experiences they have had at City of Hope with the community at large.
For Spanish-Speaking Hispanics, Entering the U.S. Healthcare System Can Be Like a Trip to a Foreign Country…or Outer Space

28/10/2013 05:32pm | 534 views

Picture yourself after a long flight to a Spanish-speaking country. You’re in the airport, tired and hungry, desperately needing to find a restroom before trying to make your way to the right luggage carousel and transportation. But all the signs you see are in Spanish and you don’t speak or read the language.

→ read more
Successes

Key Partnerships

- **Human Resources**
  Stephanie Neuvirth, Chief HR and Diversity Officer, and Kenna Cottrill, OD Consultant, and The Latino Enterprise Initiative

- **Diversity and Inclusion Council**
  - Revamp of COH’s Spanish language website
  - Healthy Hispanic Living online magazine with feature articles from Nellie, Liz & Blanca
Successes

Key Partnerships continued

- **The Biller Resource Center** – utilizes El Concilio’s feedback to enhance BRC events and programs

- **Patient Education** – utilizes El Concilio’s feedback to enhance educational materials and workshops for the Spanish-speaking community
Successes

Council Expansion and Education

- **Intensive recruitment led from 5 to 10 members**
- **Provided continued training/education via**
  - Patient and Family Centered Care (PFCC) Intensive Training Seminar in SF: March 31–April 4, 2014
  - Campus Tour: June 4, 2014
    - New patient Services
    - Population Sciences Research Consents
    - Financial Counselors
    - Biller Resource Center
    - Evaluation and Treatment Center (urgent care)
    - Amini Blood Donor Center
Ongoing Endeavors

• Revamp recruitment strategies to include staff liaisons from outside the department

• Fill staff Co-chair position

• Expand the council’s infrastructure
  – Solidify institutional partnerships
  – Diversify staff liaison expertise and involvement
    • Latinos for Hope (staff-led organization)
    • Center of Community Alliance for Research & Education (CCARE)
    • Collaborations with Patient and Family Advisory Council
Our Pearls of Wisdom

• Don’t Reinvent the Wheel
  – Borrow and modify from other programs
    • The Institute for Patient and Family Centered Care has webinars and educational materials for direction
    • Use other models of patient councils for guidelines
      – We used the model of the Patient and Family Advisory Council at COH and resource/education from other non-cancer Spanish PFAC’s to meet our needs
Pearls of Wisdom

• **Leadership Matters**
  – Co-chairs with vision, drive and commitment
  – Dedicated staff members
  – Established administrative support
  – Incorporate mentorship, skills-building and education for both staff and members

• **Find Staff Champions**
  – Sponsors and mentors
    • Key stakeholders that will support the efforts and link to opportunities and initiatives
Pearls of Wisdom

- Evaluation is an on-going process

“I’m interested in hearing your feedback. Hanson, pass out the feedback I’m interested in hearing.”
Pearls of Wisdom

• Re-evaluation
  – What is working/what is not
  – Foster and model transparency
  – Reevaluate commitments
  – Take time off for this process if needed

*For more information on our process, view our story at:
Thank you!

Coming together is a beginning. Keeping together is progress. Working together is success.

-Henry Ford