Couples Coping with Cancer Together: A Social Work Led Program for Breast Cancer Patients and Partners Integrated into Medical Care

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Duarte, CA
AOSW National Conference
May 20, 2015
Seattle, Washington
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• Courtney Vito, MD
CORE TEAM

- Patients and Partners
- Karen Clark, MS
- Terry Hernandez, Patient Navigator
- Laura Kruper, MD
- Matthew Loscalzo, LCSW
- Joanne Mortimer, MD
- Debra Vasquez, RN
- Courtney Vito, MD
- James Waisman, MD
Objectives

1. Describe the literature used in the development of the Couples Coping with Cancer Together program

2. Provide detailed information on Couples Coping with Cancer Together program components, distress screening, and satisfaction survey data

3. Discuss a program development model and leadership skills used to create and lead Couples Coping with Cancer Together
Overview of Cancer and Gender Literature

- Gender is shown to be an important component in coping and stress interventions
  - Women and men respond differently to stress (Taylor, 2006)
    - “fight or flight” for men
    - “tend and befriend” for women

- Individual levels of distress are determined more by gender than by patient-partner role
  - Women reported consistently more emotional distress than men, regardless of their role (Hagedoorn, 2008)
Overview of Cancer and Gender Literature

- **Women with breast cancer have better adjustment to their illness if their partners provide emotional support** (Baucom, 2009)
  - Women report men are better at instrumental than emotional support (Fergus, 2009)

- **Partners are an important source of support that can not be replaced by other types of support**
  - Positive relationships with many supportive friends does not make up for a problematic relationship with a single partner (Pistrang, 1995)
Overview of Cancer and Gender Literature

- 42% (287) of couples actually report the breast cancer diagnosis brought them closer
  - Preexisting marital satisfaction was not a predictive of getting closer (Dorval, 2005)

- Few successful models of partner support focus on
  - Identifying and appreciating the unique contributions from each gender
  - Integration into standard medical care
Goal: Create a model program of patient and partner support for national replication that includes

- Integration into standard medical care
- **Counseling and support for patients and partners** to help them support each other and solve problems with one another along the continuum of care
- Education and community outreach
Key Program Components

- Integration into standard medical care
- Tailored *SupportScreen* distress screening
- Standardized couples session
- Satisfaction survey
- Group intervention
- Short-term couples counseling
- Community and professional education
PARTNERS CLINIC: A GENDER-STRENGTHS BASED INTERVENTION FOR BREAST CANCER PATIENTS AND THEIR PARTNERS

**STEP 1**
Patient Identification/Screening
Patient (PT) calls for initial surgical consultation
PT screened for Partners Clinic

**STEP 2**
Orientation
Patient Navigator guides PT and Partner through the Partners Clinic process

**STEP 3**
Distress Screening
PT and Partner both complete SupportScreen automated problem-based biopsychosocial screening

**STEP 4**
Education and Psychological Support
PT and Partner meet with male/female Clinician-educators

**STEP 5**
Surgical Consultation
PT and Partner meet with Surgeon and can immediately practice new skills and knowledge

**STEP 6**
Satisfaction Data Collection
PT and Partner complete touch screen satisfaction survey

**STEP 7**
Documentation
Intervention is documented in the electronic medical record
Distress Screening

- City of Hope developed and validated a biopsychosocial screening tool called the *SupportScreen*

- The *SupportScreen-Couples* is tailored to identify the unique needs of breast cancer Patients and Partners

- Patients and Partners complete the touchscreen survey identifying areas of distress and informational needs prior to their consultations
  - *SupportScreen* is aligned with the Couples Program core principle of open and honest communication from the very first encounter

- Results are e-mailed to the healthcare team in real time
Distress Screening Content

- **Biopsychosocial distress**
  o Physiological, Psychological, Emotional, Social, Practical, Spiritual

- **Motivational questions**
  o How much is this a problem for you?
    - “Being able to depend on my Partner no matter what”
    - “Being honest with my Partner about my concerns”

- **Educational questions**
  o How much is this a problem for you?
    - “Recognizing that I need to be supportive, but I cannot be responsible for keeping my Partner’s spirits up “
    - “Being so reassuring that my Partner thinks I cannot listen to her concerns”
Standardized Couples Session
Normalizing, Destigmatizing, and Giving Hope

- A standardized couples session for new Patients and their Partners prior to initial consultation with physician
  - Communicate that Patient and Partner concerns are paramount
  - Normalize differences in communication and coping
  - Share wisdom from past Patients, Partners, research and our clinical experience
  - Provide concrete and practical behaviors to best support and problem solve with one another during times of stress
  - Reinforce that many couples grow closer to one another despite stressors
Practicing Helpful Behaviors

• Immediately following couples session Patient and Partner meet with their physician for initial consultation

  o Patient and Partner can immediately practice the practical behaviors with one another during the clinical encounter
  o Partners are encouraged to be an active member of the medical care and team
  o Addressing psychosocial needs prior to medical consultation allows the Physician, Patient, and Partner to focus on medical information
Short Term Couples Counseling

- Psychoeducational
  - Educating couples about their illness, treatment, and coping skills while integrating supportive therapeutic components

- Gender-strengths based
  - Every person has unique strengths
  - Importance of valuing differences, and the need to collaborate

- Problem Solving Skills Training Therapy
- Communication Skills Training Therapy
- Cognitive Behavioral Therapy
Group Intervention
Couples: Essential Skills for Overcoming the Challenges of Cancer Together

- **Monthly Group**
  - Co-facilitated with Matthew Loscalzo
  - Open to all City of Hope Patients and Partners

- **Feedback from participants**
  - “I really liked the informal format. It is very enlightening to listen to other people’s experiences and find differences and similarities”
  - “It was helpful to hear techniques to focus on issues and share ideas to get there without the drama i.e. key words, ways men vs. women process conflict”

- **Future topics requested by participants**
  - “What are ways we can reconnect when anger and resentment do occur?”
  - “Since my partner's cancer is incurable, how can I talk about death but not make him feel like I have given up?”
Distress Screening Data
Patient Demographics

- Data was collected from January 2014 – March 2015
- 202 Patients and 183 Partners screened
- Average age was 56 years old
- Patients were 51% Caucasian, 21% Latino and 18% Asian
- 50% of Patients and Partners had a college degree or advanced education
## Patient and Partner Distress Screening

**Issues Rated Moderate to Very Severe**

<table>
<thead>
<tr>
<th>Patients (n=202)</th>
<th>% High Distress</th>
<th>Partners (n=183)</th>
<th>% High Distress</th>
</tr>
</thead>
<tbody>
<tr>
<td>Side-effects of treatments</td>
<td>58%</td>
<td>Feeling anxious or fearful</td>
<td>29%</td>
</tr>
<tr>
<td>Feeling anxious or fearful</td>
<td>47%</td>
<td>Worry about the future</td>
<td>29%</td>
</tr>
<tr>
<td>Worry about the future</td>
<td>46%</td>
<td>Finances</td>
<td>21%</td>
</tr>
<tr>
<td>How my family will cope</td>
<td>42%</td>
<td>Sleeping</td>
<td>18%</td>
</tr>
<tr>
<td>Sleeping</td>
<td>38%</td>
<td>Fatigue</td>
<td>17%</td>
</tr>
</tbody>
</table>
Patient Problem-Related Distress Data Analysis

- High distress in **Worry about the future** is significantly correlated (p=.000) with:
  - Feeling anxious or fearful
  - Feeling down or depressed
  - How my family will cope
  - Managing my emotions
  - Questions and fear about end of life
  - Side effects of treatments

- High distress in **How my family will cope** is significantly correlated (p=.000) with:
  - Managing my emotions
  - Managing work school and home life
  - Questions and fear about end of life
  - Worry about the future

- High distress in **Sleeping** is significantly correlated (p=.000) with:
  - Feeling down or depressed
Partner Problem-Related Distress Data Analysis

- High distress in *Worry about the future* is significantly correlated (p=.000) with
  - Feeling anxious or fearful
  - Feeling down or depressed
  - Losing control of things that matter to me
  - Managing my emotions

- High distress in *Fatigue* is significantly correlated (p=.000) with
  - Feeling down or depressed
  - Losing control of things that matter to me
  - Sleeping
  - Transportation

- High distress in *Sleeping* is significantly correlated (p=.000) with
  - Fatigue
  - Feeling down or depressed
  - Feeling anxious or fearful
Satisfaction Survey Data

- Data collected from August 2014 - March 2015

- Patients and Partners complete an electronic satisfaction questionnaire immediately after the MD consult

- Questions tailored for each member of the team
  - Debra Vasquez, RN New Patient Services
  - Terry Hernandez, Patient Navigation
  - Physician
  - Courtney Bitz, LCSW
### Satisfaction Survey Data

<table>
<thead>
<tr>
<th>Statements</th>
<th>% Agree/Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Courtney Bitz shared information that helped us to understand the problems</td>
<td>94%</td>
</tr>
<tr>
<td>women and their partners have to manage together</td>
<td>96%</td>
</tr>
<tr>
<td>Courtney Bitz shared information that could help us to cope better with</td>
<td>93%</td>
</tr>
<tr>
<td>the current situation</td>
<td>97%</td>
</tr>
<tr>
<td>Courtney Bitz shared information that helped me and my partner understand</td>
<td>94%</td>
</tr>
<tr>
<td>how we can work as a team</td>
<td>97%</td>
</tr>
<tr>
<td>I feel Dr. __________ and I can work as a team</td>
<td>96%</td>
</tr>
<tr>
<td>Dr. __________ was able to answer all of our questions</td>
<td>96%</td>
</tr>
<tr>
<td></td>
<td>97%</td>
</tr>
</tbody>
</table>
Satisfaction Survey Data - Continued

<table>
<thead>
<tr>
<th></th>
<th>% Agree/Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Patients (n=115)</td>
</tr>
<tr>
<td>Terry Hernandez, the Patient Navigator, provided me with personalized guidance</td>
<td>87%</td>
</tr>
<tr>
<td>Terry Hernandez was able to answer all of our questions</td>
<td>87%</td>
</tr>
<tr>
<td>Debra Vasquez clearly explained the process for becoming a patient at City of Hope</td>
<td>91%</td>
</tr>
<tr>
<td>When calling for my first appointment, the new patient services representative was helpful</td>
<td>92%</td>
</tr>
<tr>
<td>I recommend this program, for other women and their partners</td>
<td>93%</td>
</tr>
</tbody>
</table>
Program Benefits

- Manages Patient and Partner distress proactively and in a timely manner
- Provides Patients and Partners tailored support throughout cancer continuum
- Facilitates collaboration and coordination with multi-disciplinary team
- Offers peer support through group interventions
- Patients and Partners can use the skills learned to manage future stressors
Program Development History

• March 2011
  • The team launched a pilot program to determine feasibility of integrating a psychosocial couples intervention prior to the initial surgical consultation
  • One surgeon; one evening clinic

• March 2011- October 2013
  • Additional surgeons requested intervention
  • Collected data from the Patient/Partner distress screening and satisfaction survey
  • Refined the components of the intervention and we learned a lot
  • Developed posters and presentations –we wouldn’t stop talking about the program
  • Members of our team diligently sought funding for expansion of the couples program
Program Development History- Continued

• October 2013- (2 years, 7 months and two days later)
  • A grateful Patient made a donation to fund a two year expansion of the partners clinic in Women’s Cancer Program
  • Funding was used to staff full time program coordinator/clinician
  • Information from the feasibility study was used to build a comprehensive program

• October 2013-May 2015
  • Used a concurrent program development model
  • Set up infrastructure in a complicated medical system
  • Built relationships with stakeholders
  • Expanded the program into medical oncology
  • Developed additional intervention components
  • Continued collecting data
Vision for the Future

- Expansion of program to additional Patient populations
  - Avon-Pfizer Grant to tailor program for Metastatic Breast Cancer
  - Focus group for same sex couples
- Analyze distress screening data to refine the screening instrument
- Develop performance outcome measures and introduce research components
- Website and social media
- Gender-strengths based couples counseling trainings for professionals
- Author additional peer reviewed journal articles and present at national professional conferences to support our efforts of program replication
Building a Program: It REALLY Takes a Village

- Patients and their partners
- Private Philanthropy
- Rosemary Aldana, New Patient Services
- Jocelyn Arranaga, Clinical Research Nurse
- Ana Avila, ACA
- Ruby Banuelos, MSW
- Courtney Bitz, LCSW
- Karen Clark, MS
- Nancy Clifton-Hawkins, MPH, MCHES
- Suzanne Diller-Volunteer
- Amy Donner, LCSW
- Brett Evans, Operations Manager-SupportScreen
- Nellie Garcia, LCSW
- Gayle Gilbert-Hamerling- Director of Volunteer Services
- Terry Hernandez, Patient Navigator
- Linda Klein, JD Manager of BRC Operations
- Laura Kruper, MD
- Jeanne Lawrence-BRC Navigator
- Ellen Liu, NP
- Matthew Loscalzo, LCSW
- Leticia Magdaleno, ACA
- Marion Maher, BSN

- Aleksandra Markowski, Breast Center Assistant
- Annette Mercurio, MPH, MCHES
- Susan Mischenko, Clinical Nurse II
- Marlena Moe, Manger Breast Imaging & Operations
- Janet Morgan, Development
- Sharla Moore, Program Manager
- Diane Morrison, LCSW
- Joanne Mortimer, MD
- Charlene Nuno, PA
- Richard Obenchain, Senior Systems Analyst – SupportScreen
- Dawnyetta Reese, Sr. Administrative Support
- Lori Rezabek-Kells, NP
- Joan Rhoa, RN
- Carmen Sedgeman, NP
- David Trejo, BS, Lead Patient Navigator
- Debra Vasquez, RN
- Courtney Vito, MD
- James Waisman, MD
- Rosalyn Wilson, ACA
- Louise Wong, NP
- Tiffany Yang M.S., CCLS
Couples Coping with Cancer Together

If you have any additional questions, please feel free to contact me directly.

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