Joy Luck Academy: 
A Social Support Intervention among Chinese-Speaking Breast Cancer Survivors

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• Community Partners
  – Herald Cancer Association
Need for Psychosocial Interventions

• More than 400 trials of psychosocial interventions among non-Hispanic white cancer survivors
  – A variety of health benefits
    • Reduced risks of breast cancer recurrence and mortality (Andersen et al., 2008, Spiegel et al., 1989), cancer related morbidity (Stanton, 2002), depressive symptoms (Marchioro et al., 1996)
    • Improved quality of life (Marchioro et al., 1996) and physical functioning (Helgeson et al., 1999)

• Few interventions among minorities
  – Limited intervention studies among African Americans (Schover et al. 2006, Mishel, 2005)
  – Hispanic cancer survivors (Greenlee, 2015)
  – Lack of intervention among Asian cancer survivors
Asian American Breast Cancer Survivors

- Breast cancer is the most common invasive cancer in women.

- Breast cancer is the leading cancer among some Asian American women (e.g., Chinese, Filipino, Hawaiian, Japanese, and Korean).

- Asian American (AA) Breast cancer survivors experience
  - Distress: depression, anxiety, fear,
  - Stigma, shame, isolation…
“When I found that I had cancer, I cried. I didn't know how to face it; I wept everyday. …Unable to face the huge negative impact that cancer had on my life, I was devastated… I was lonely, felt hopeless, and cried daily.”

“I felt inferior to others because of breast cancer. One time I went to a friend’s party and she had a baby. While everyone hugged and kissed the baby, I avoided doing that because I was afraid of bringing bad luck to the baby. I now avoid going to social gatherings.”

------Chinese speaking breast cancer survivors

- Lack of knowledge about breast cancer and treatment
  - Link breast cancer with immediate death
  - Mastectomy is better
  - Misattribution
- Emotional and relational needs
  - Lonely, concealing BC.
  - Problems in communication and intimate relationships
  - Body image issues
- Language barrier

American Cancer Society (No. MRSGT-10-011-01-CPPB. PI: Qian Lu)
Step Two: Program Development: Intervention Design Theoretical Rationale

- Informational needs
- Emotional needs
- Education
- Peer Mentor Support
CBPR: University of Houston
Herald Cancer Association
“One Of The Year’s Best Films!”
— ABC TV

“Two Thumbs Up, Way Up!”
— Salon & Short

“An Extraordinary Film!”
— Good Morning America

THE JOY LUCK CLUB
An Oliver Stone Production
Step Three: Joy Luck Academy (JLA) Program

• **Education Curriculum**
  – Six-ten weekly sessions
  – Knowledge about breast cancer and treatment:
    • Post-treatment issues, physical therapy/alternative medicine, diet and nutrition
  – Family and emotional needs
    • Communication, emotion management, body image issues
  – Delivered by professionals in Chinese (physician, dietitian, psychologist, physical therapist…)

• **Mentors**
  – Chinese breast cancer survivor volunteers
  – Trained to provide emotional support
  – Matched based on disease status, language, and country of origin
Pilot Study: Outcomes of Joy Luck Academy (JLA) (Lu et al., 2014)

![Bar chart showing outcomes of depression, anxiety, positive affect, and negative affect with baseline and follow-up data.](chart.png)

- Depression: Baseline 0.88, Follow-up 0.48
- Anxiety: Baseline 1.03, Follow-up 0.68
- Positive Affect: Baseline 2.55, Follow-up 3.0
- Negative Affect: Baseline 1.82, Follow-up 1.57

*Significant difference at the 0.05 level.
Step Four: Current Study:
JLA RCT Aims and Hypotheses

- A randomized controlled trial (RCT) among Chinese-speaking breast cancer survivors.

- Aims:
  - To test the health benefits of the JLA program
  - To identify for whom and why the JLA works

- Primary hypotheses:
  - The JLA will confer health benefits.

- Community based participatory research (CBPR) approach

- Mixed deductive and inductive methods
**Figure 1: Joy Luck Academy Intervention Design Rationale**

- **Needs assessment**
  - Lack of emotional support / Loneliness
  - Limited English proficiency
  - Lack of knowledge and skills

- **Culturally tailoring Intervention**
  - Emotional support
    - Peer mentorship
    - Education

- **Theory and Mechanisms**
  - Belongingness $\uparrow$
  - Stigma $\downarrow$
  - Self-efficacy $\uparrow$

- **Health outcomes**
  - Quality of life $\uparrow$
  - Positive affect $\uparrow$
  - Fatigue $\downarrow$
  - Depression $\downarrow$
  - Perceived stress $\downarrow$
  - Cortisol $\downarrow$
JLA Program

Sharing

Lecture
JLA Mentors
Methods

Recruitment & Eligibility screening

Group allocation (JLA vs. Wait-list)

Consent, Baseline Questionnaire, & Baseline Saliva collection (Orientation)

JLA Intervention, Process evaluation, & Focus group interview

1 week

Waitlist Control group

Follow-up Questionnaire 1 & Saliva collection

Follow-up Questionnaire 2 (1 month)

Follow-up Questionnaire 3 (4 months)

Individual interview
# Recruitment and Retention

<table>
<thead>
<tr>
<th>Number of Participants</th>
<th>Cohort 1-JLA</th>
<th>Cohort 2-JLA</th>
<th>JLA total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recruitment goals</td>
<td>24</td>
<td>24</td>
<td>48</td>
</tr>
<tr>
<td>Recruited</td>
<td>19</td>
<td>29</td>
<td>48</td>
</tr>
<tr>
<td>Intervention</td>
<td>9</td>
<td>18</td>
<td>27</td>
</tr>
<tr>
<td>Control</td>
<td>10</td>
<td>11</td>
<td>21</td>
</tr>
<tr>
<td>Dropout</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Crossover</td>
<td>None</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>Cortisol sample</td>
<td>19</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Follow-up 1(post-test)</td>
<td>18</td>
<td>Ongoing</td>
<td>18</td>
</tr>
<tr>
<td>Follow-up 2(1 month)</td>
<td>18</td>
<td>Planning</td>
<td>18</td>
</tr>
<tr>
<td>Follow-up 3(4 month)</td>
<td>18</td>
<td>Planning</td>
<td>18</td>
</tr>
<tr>
<td>Focus group interview</td>
<td>5</td>
<td>5</td>
<td>10</td>
</tr>
<tr>
<td>Individual interview</td>
<td>9</td>
<td>Planning</td>
<td>9</td>
</tr>
</tbody>
</table>

Retention rate: 95%
Changes in Health Outcomes (Cohort 1, N=18)

FACT-B QoL

$p = .004$

Social QoL

$p = .055$
Changes in Health Outcomes (Cohort 1, N=18)

QoL - Additional concerns

Low arousal positive affect

$p = .082$

$p = .074$
Cohort One Cortisol Results (N=12)

Steeper cortisol slope after the intervention 😊
Conclusions

- **Challenges**
  - Community based programs—change
  - Non-English speaking populations: two versions for all study materials

- **Lessons learned and solutions**
  - Quality control and standardization
    - Detailed planning (to the day/hour/minute)
    - Monitoring, control, and correction (Weekly)
    - Detailed manuals for the JLA program and mentor training---dissemination
  - Professional project management
    - Bi-lingual and bi-cultural competence
    - Personnel vs. team

- **Success**
  - Building trust and support from community and participants
  - Encouraging initial results
  - Successful recruitment
  - High retention rate
  - Cortisol collection is feasible—first time in AABCS community!
  - Manuals will be ready for dissemination by the end of the project
Thank you!

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# Intervention Content

<table>
<thead>
<tr>
<th>Week</th>
<th>Topic</th>
<th>Lecture</th>
<th>Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Breast cancer overview</td>
<td>Treatments, Hereditary BC, symptoms, Follow-up care</td>
<td>Mentor sharing, Icebreakers</td>
</tr>
<tr>
<td>2</td>
<td>Self-care for survivors</td>
<td>Lymphedema prevention &amp; detection, Exercise, Complementary medicines</td>
<td>Collage of cancer experience</td>
</tr>
<tr>
<td>3</td>
<td>Diet &amp; nutrition</td>
<td>Nutrition, Long-term healthy diet, Fads &amp; facts, Supplements</td>
<td>Portion size activity, Goal setting</td>
</tr>
<tr>
<td>4</td>
<td>Communication</td>
<td>Talking with friends, family, &amp; healthcare workers</td>
<td>Role-play, Writing a card to loved ones</td>
</tr>
<tr>
<td>5</td>
<td>Rebuild a New Me</td>
<td>Self-image, Stress &amp; emotional management</td>
<td>My 8 treasures (cootie-catcher)</td>
</tr>
<tr>
<td>6</td>
<td>Beautiful Me</td>
<td>Caring for skin &amp; hair, Using prosthesis, Dressing &amp; fashion</td>
<td>My wish and dream, Write letter to yourself</td>
</tr>
<tr>
<td>7</td>
<td>Graduation</td>
<td>Graduation ceremony</td>
<td>Writing thank you notes to each other</td>
</tr>
</tbody>
</table>
Monitoring & Quality Control

Plan
- Detailed study protocol
- Develop weekly calendar and checklist for study protocol
- Program development:
  --Objectives for weekly sessions, lectures, and activities
  --Mentor training

Execution/Monitoring
- Calendar
- Checklists
- Intervention documentation
- Participants tracking

Monitoring: Review
- Session recordings
- Presentation
- Study materials
- Participants tracking
- Record deviations or modifications to the protocol

Control
- Data gathering
- Analytical processes
- Management:
  Recommended correction
  Recommended improvement

- Intervention Manual
- Mentor Training Manual
Cohort One Cortisol Results (N=12) with Norms
Methods

• Recruitment
  – Chinese community organization’s clients
  – Advertising at community events and conferences

• Eligibility criteria
  – Chinese speaking (Mandarin or Cantonese)
  – Cancer diagnosis (stages 0, I, II, III)
  – Completed treatment in last 36 months

• Covariate adaptive randomization
  – JLA group and a self-study group (wait-list control)

• Assessment:
  – Qualitative: health outcomes, cortisol
  – Quantitative: focus group, individual interview
  – Weekly process evaluation