

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

Qian Lu Ph.D. MD

Krystal Warmouth Ph.D.

Christine Wu B.S.

Nelson Yeung M.S.

Jing Xie Ph.D.

University of Houston

Alice Loh, B.S.,
Lucy Young M.S.,
Herald Cancer
Association

Disclosure and Acknowledgement

- **Disclosure**
 - No conflict of interests
 - No financial relationship(s) relevant to the content of this CME activity.
 - **Funding**
 - National Cancer Institute
(No. 1R01CA180896-01A1, PI: Qian Lu)
 - **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.”

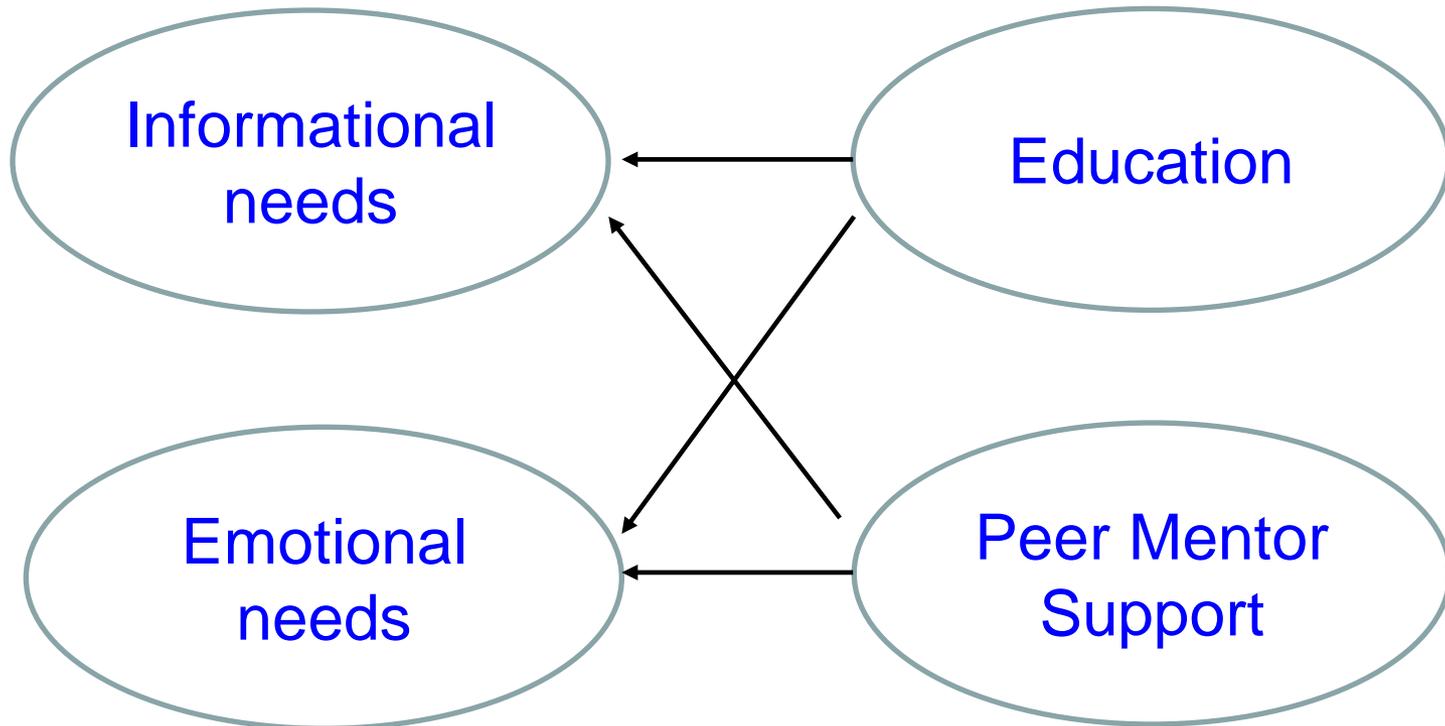
“ I felt inferior to others because of breast cancer. One time I went to a friend's party and she had a baby. While everyone hugged and kissed the baby, I avoided doing that because I was afraid of bringing bad luck to the baby. I now avoid going to social gathering. ”

-----Chinese speaking breast cancer survivors

Step one: Needs Assessment among Chinese American Breast Cancer Survivors (Lu, Yeung, Dai, You, in press)

- 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

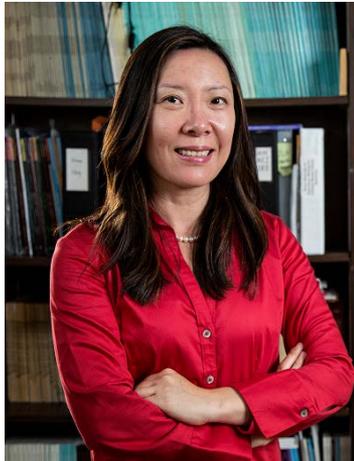
Step Two: Program Development: Intervention Design Theoretical Rationale

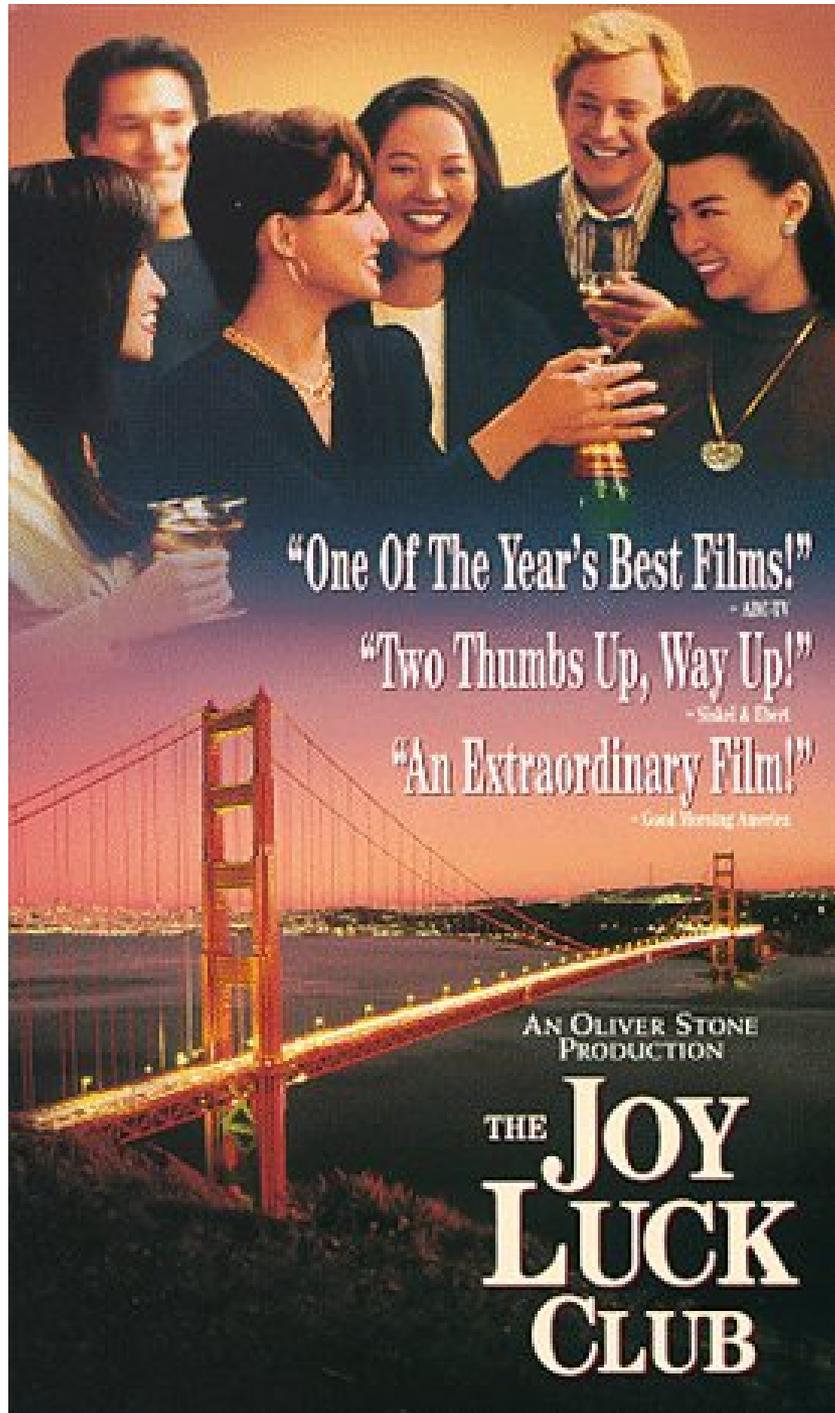




UNIVERSITY OF HOUSTON
Learning. Leading.

CBPR: University of Houston Herald Cancer Association





"One Of The Year's Best Films!"

- ABC-TV

"Two Thumbs Up, Way Up!"

- Siskel & Ebert

"An Extraordinary Film!"

- Gold Morning America

AN OLIVER STONE
PRODUCTION

THE JOY
LUCK
CLUB

Step Three: Joy Luck Academy (JLA) Program

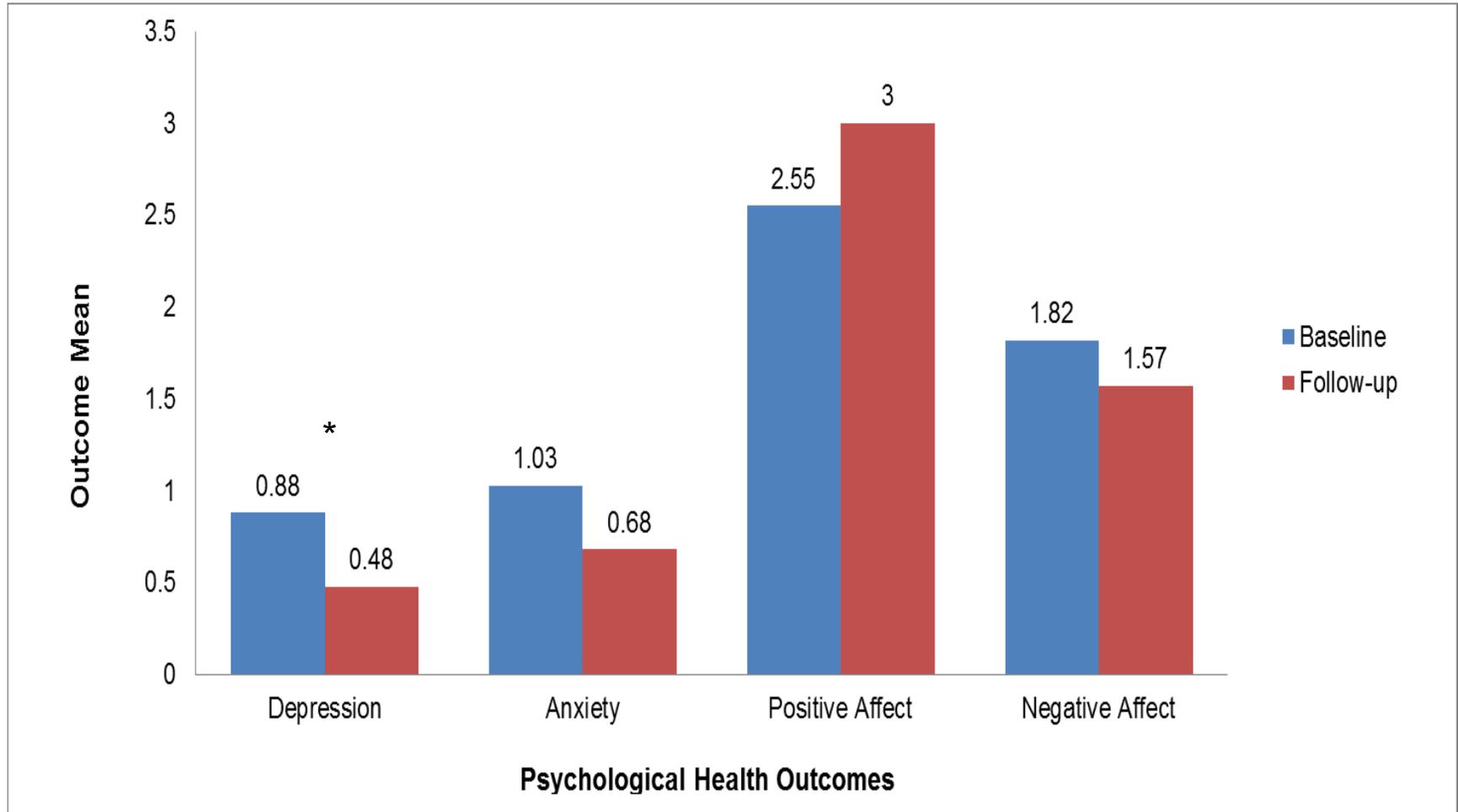
- Education Curriculum

- 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
-

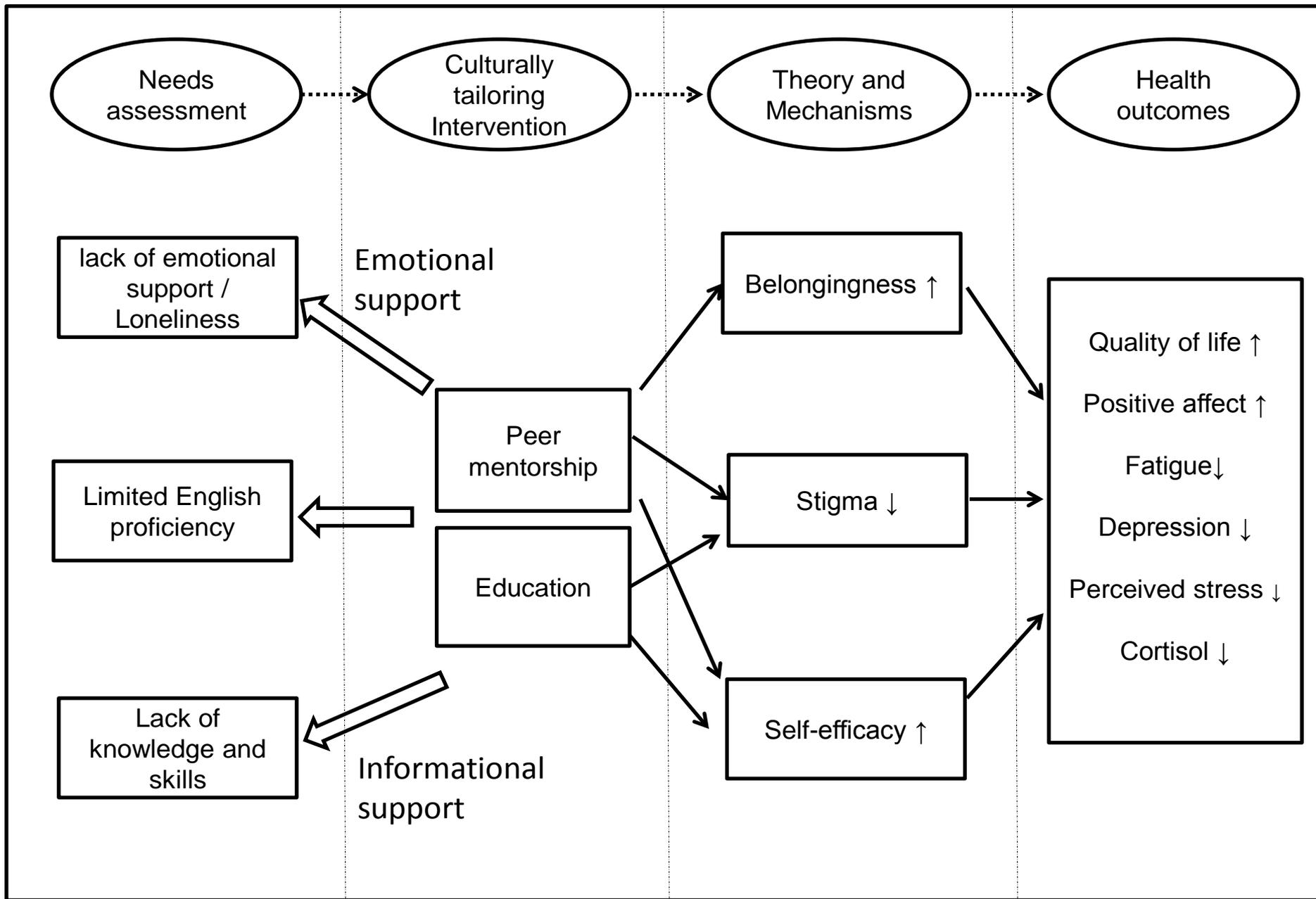
Pilot Study: Outcomes of Joy Luck Academy(JLA) (Lu et al., 2014)



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



JLA Program

Sharing



JLA Logo

開懷學苑



Lecture



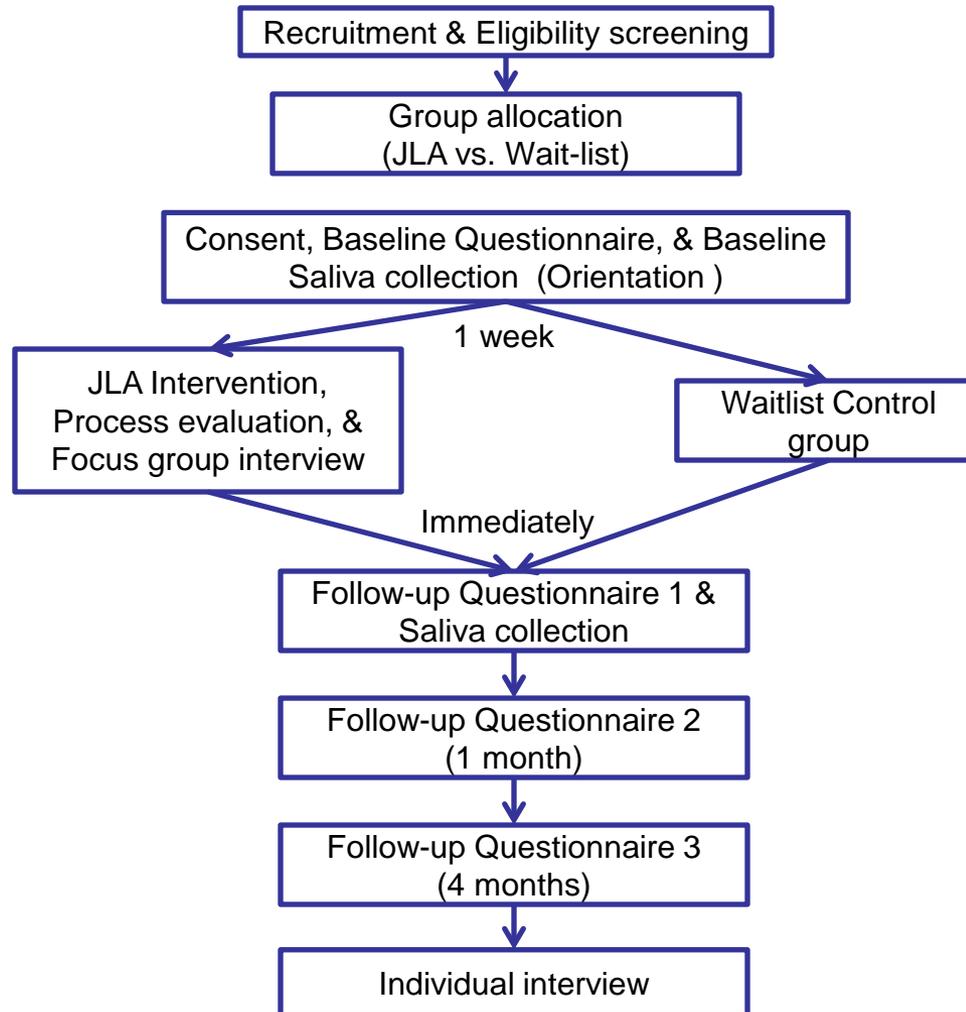
Activities



JLA Mentors



Methods

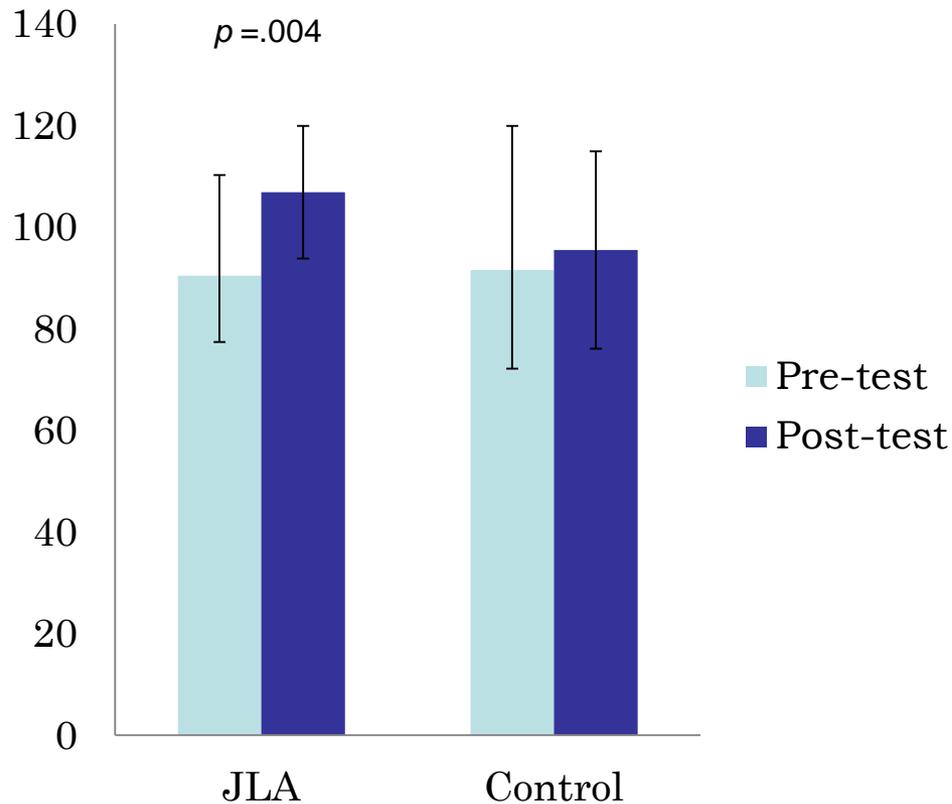


Recruitment and Retention

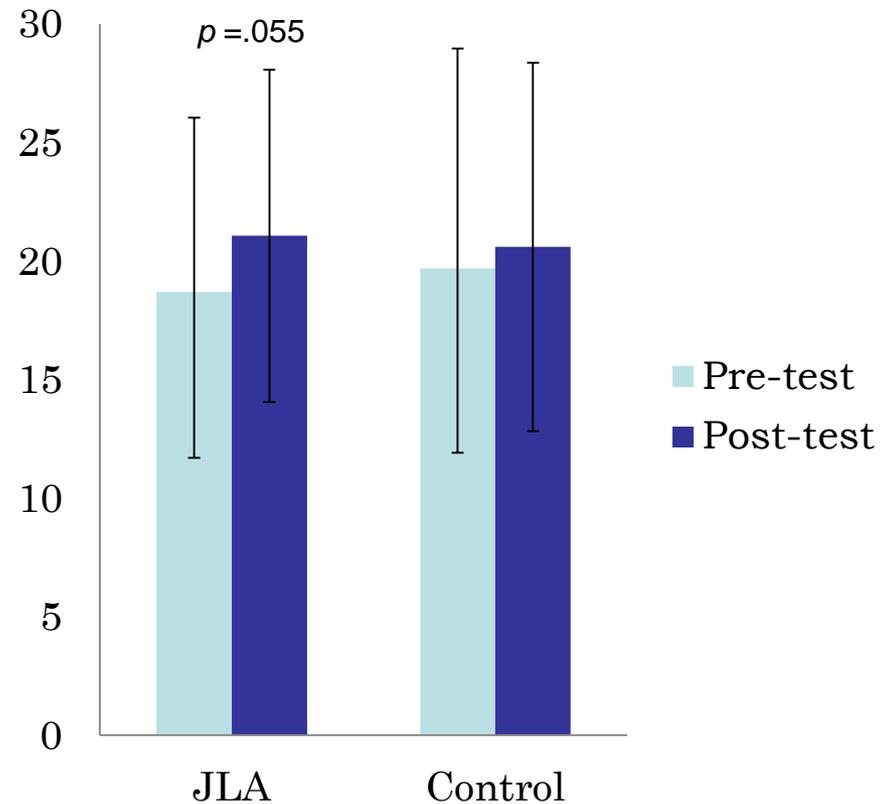
Number of Participants	Cohort 1-JLA	Cohort 2-JLA	JLA total
Recruitment goals	24	24	48
Recruited	19	29	48
Intervention	9	18	27
Control	10	11	21
Dropout	1	0	1
Crossover	None	6	6
Cortisol sample	19		
Follow-up 1(post-test)	18	Ongoing	18
Follow-up 2(1 month)	18	Planning	18
Follow-up 3(4 month)	18	Planning	18
Focus group interview	5	5	10
Individual interview	9	Planning	9
Retention rate	95%		

Changes in Health Outcomes (Cohort 1, N=18)

FACT-B QoL

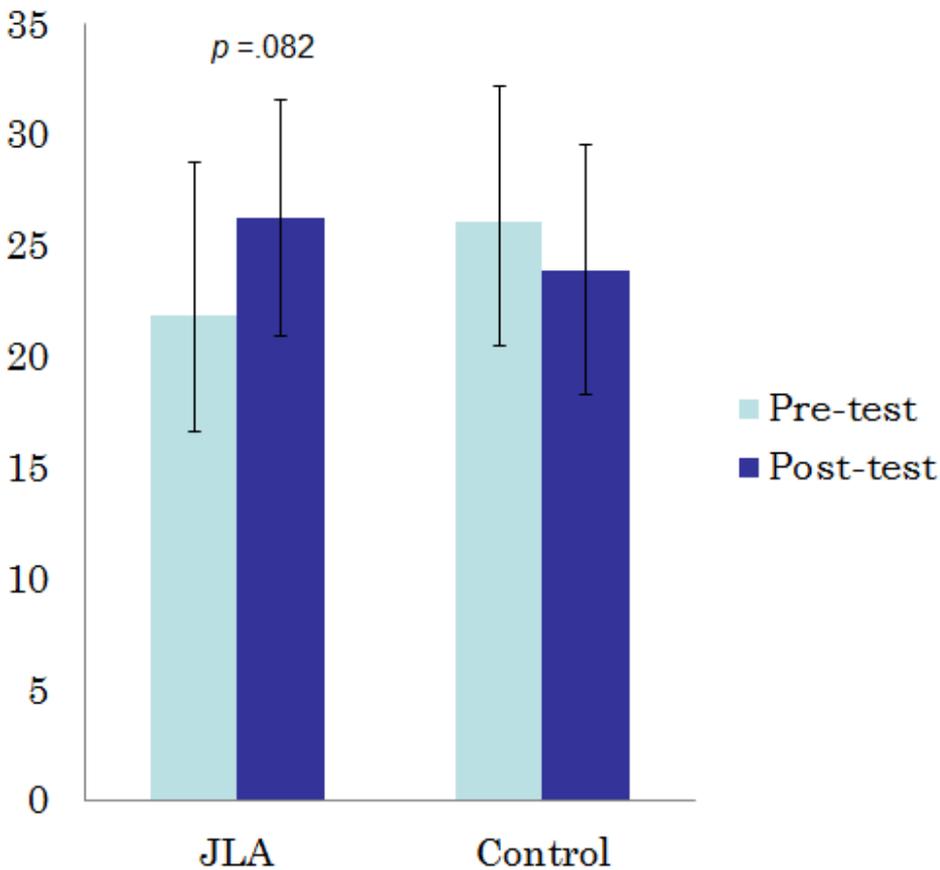


Social QoL

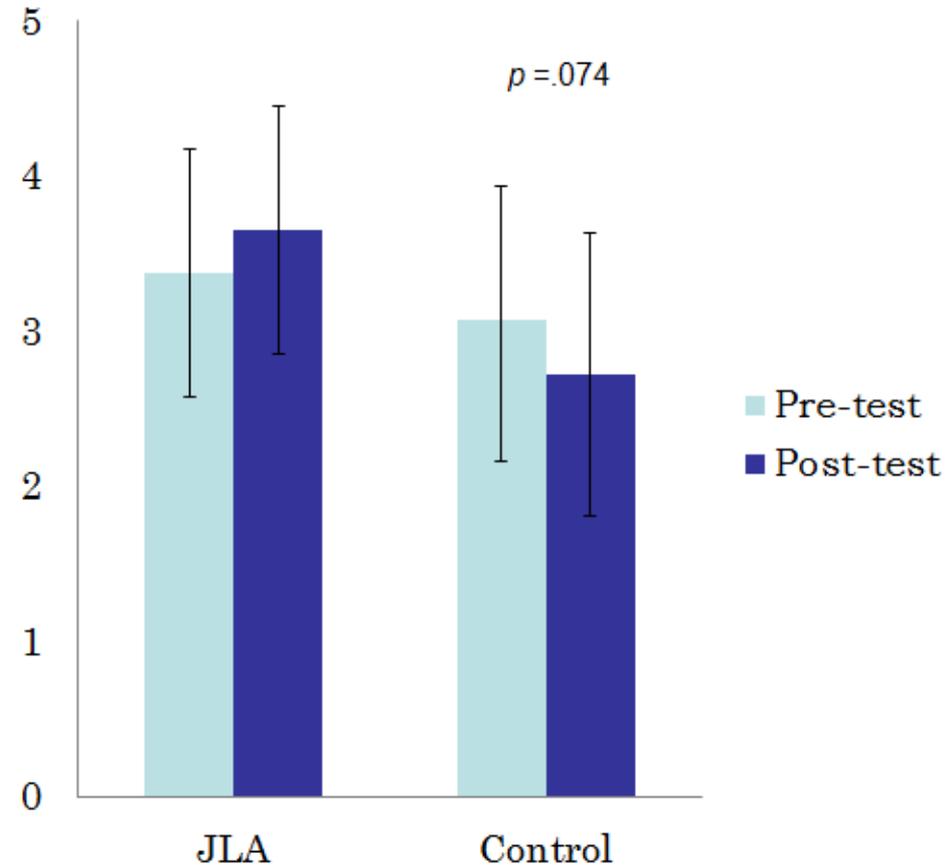


Changes in Health Outcomes (Cohort 1, N=18)

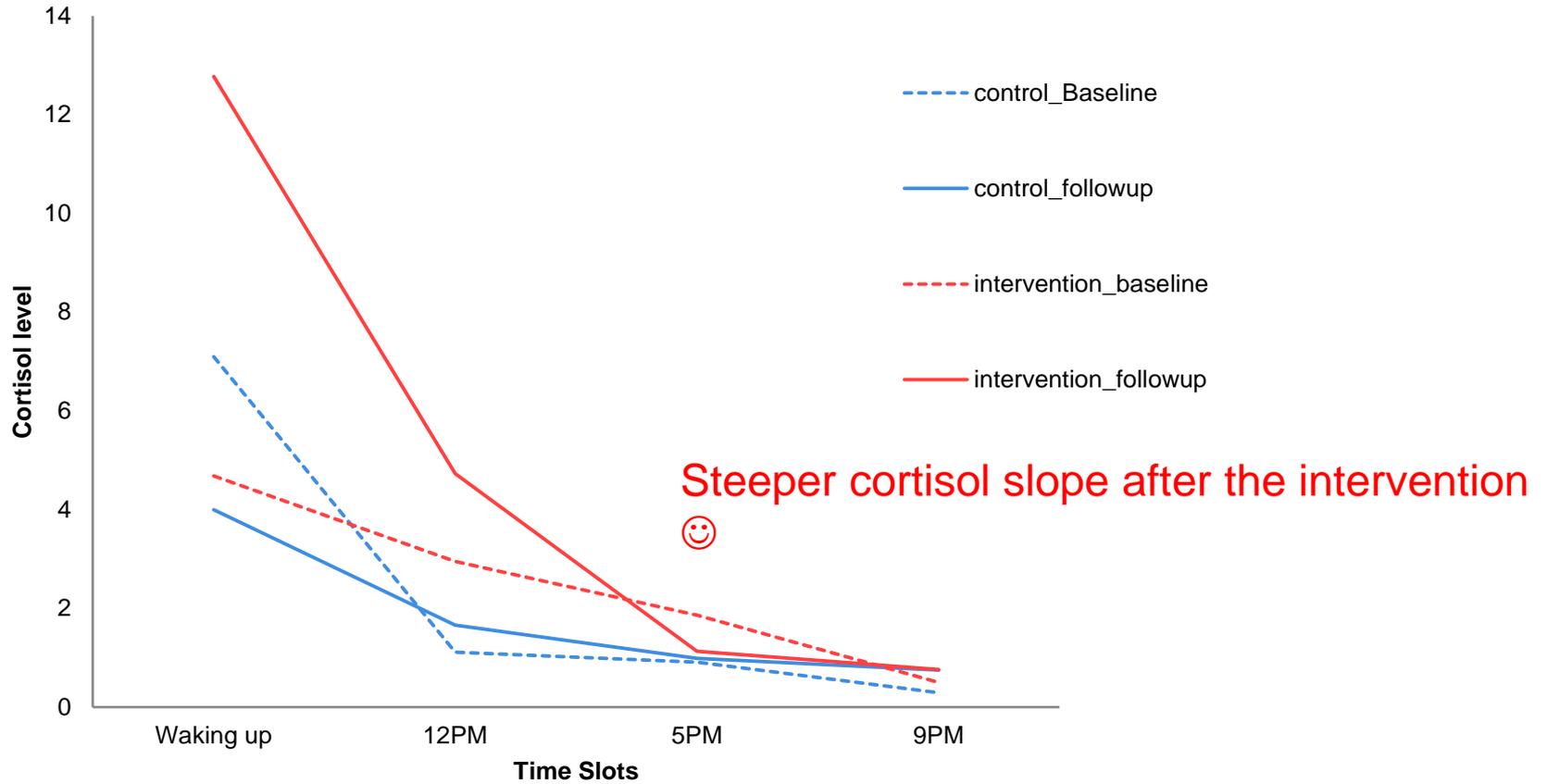
QoL - Additional concerns



Low arousal positive affect



Cohort One Cortisol Results (N=12)



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!

Qian Lu M.D Ph.D

Department of Psychology

University of Houston

Contact information: q lu.ucla@gmail.com

q lu3@uh.edu

Intervention Content

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

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

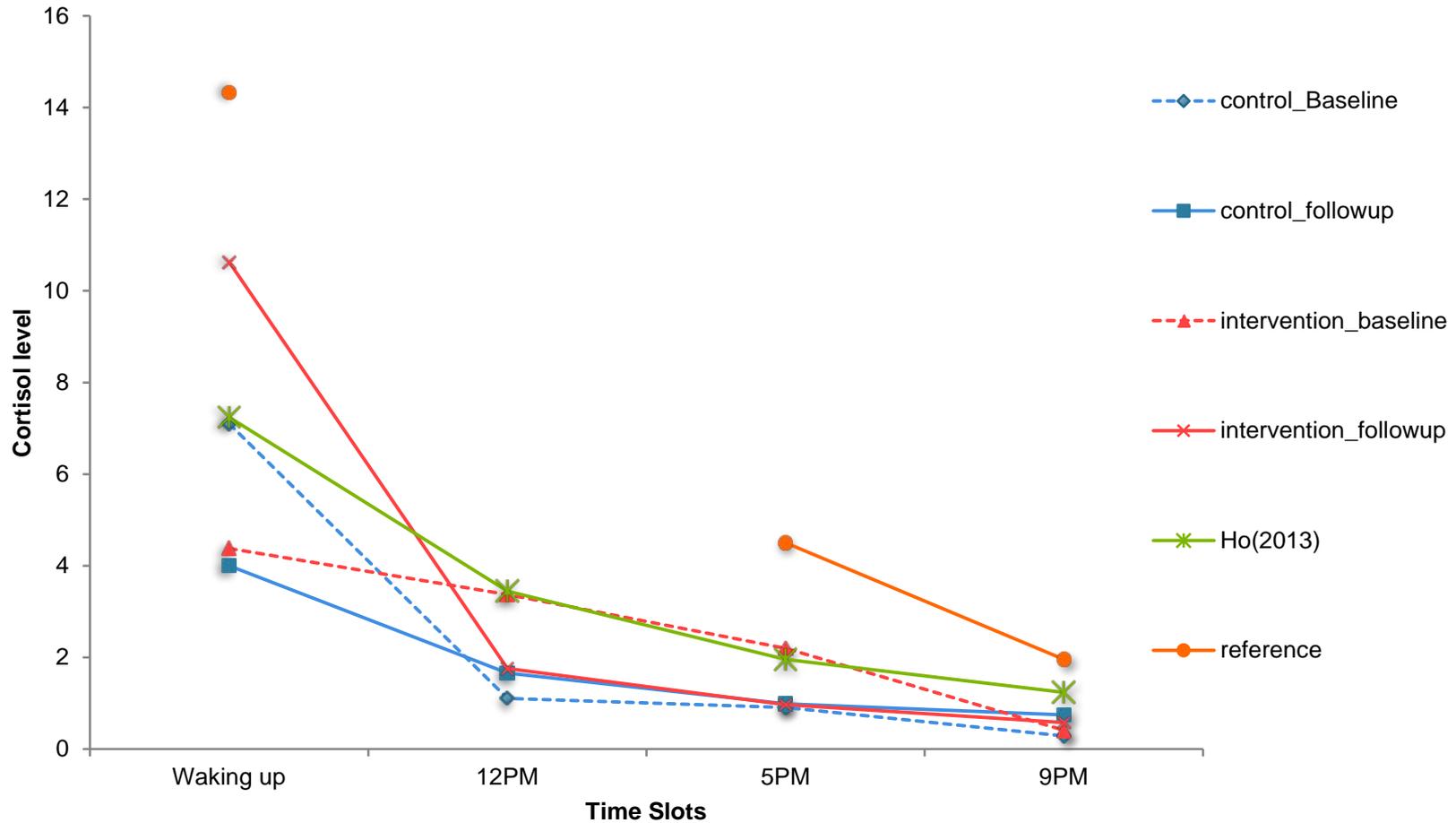
- Calendar
 - Checklists
 - Intervention documentation
 - Participants tracking
- Monitoring: Review
- Session recordings
 - Presentation
 - Study materials
 - Participants tracking
 - Record deviations or modifications to the protocol

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
-