

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

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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
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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...
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“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.”

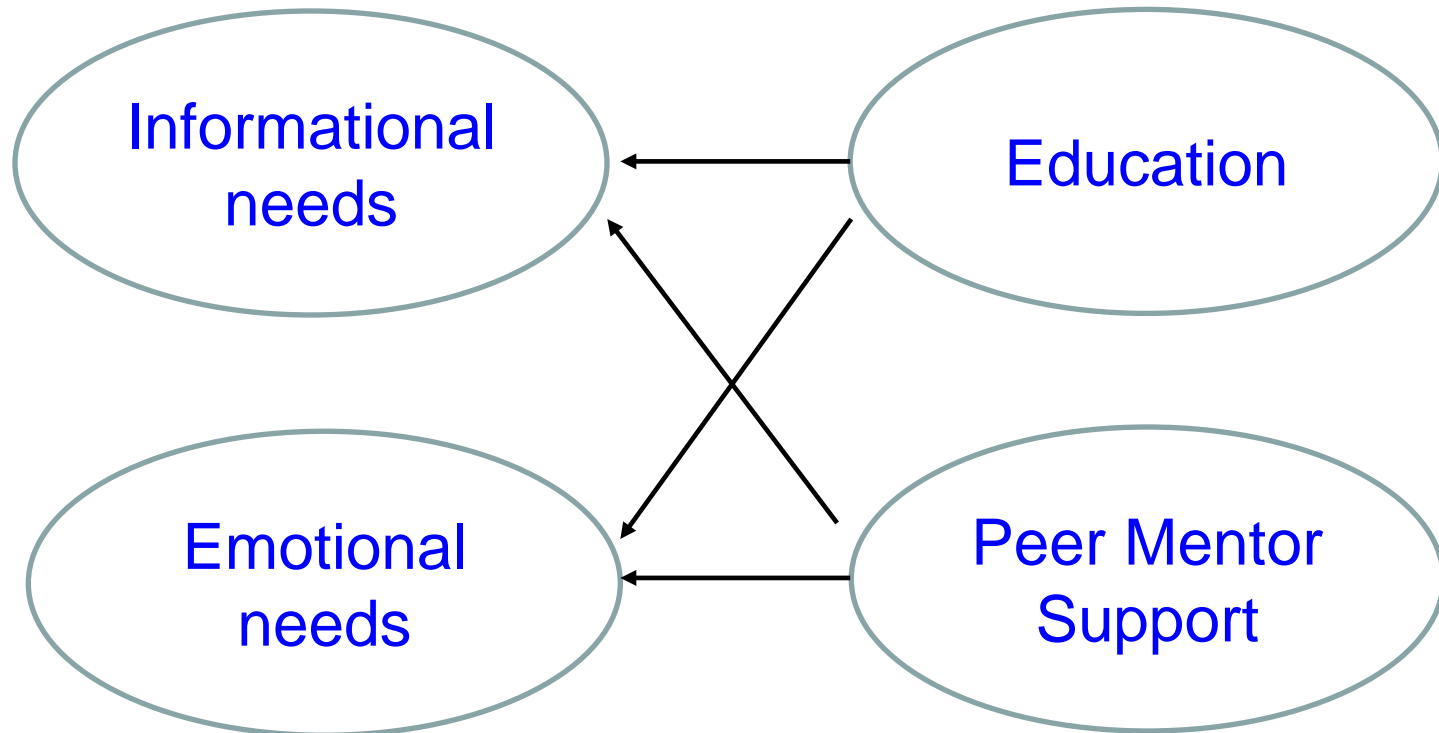
“ I felt inferior to others because of breast cancer. One time I went to a friend's party and she had a baby. While everyone hugged and kissed the baby, I avoided doing that because I was afraid of bringing bad luck to the baby. I now avoid going to social gathering. ”

-----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

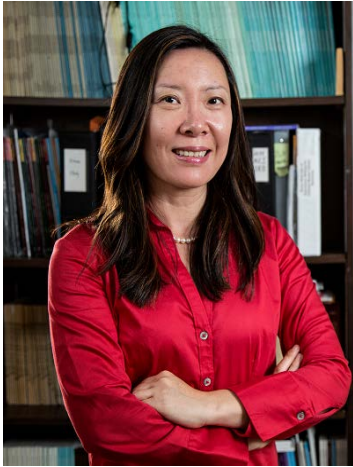
Step Two: Program Development: Intervention Design Theoretical Rationale

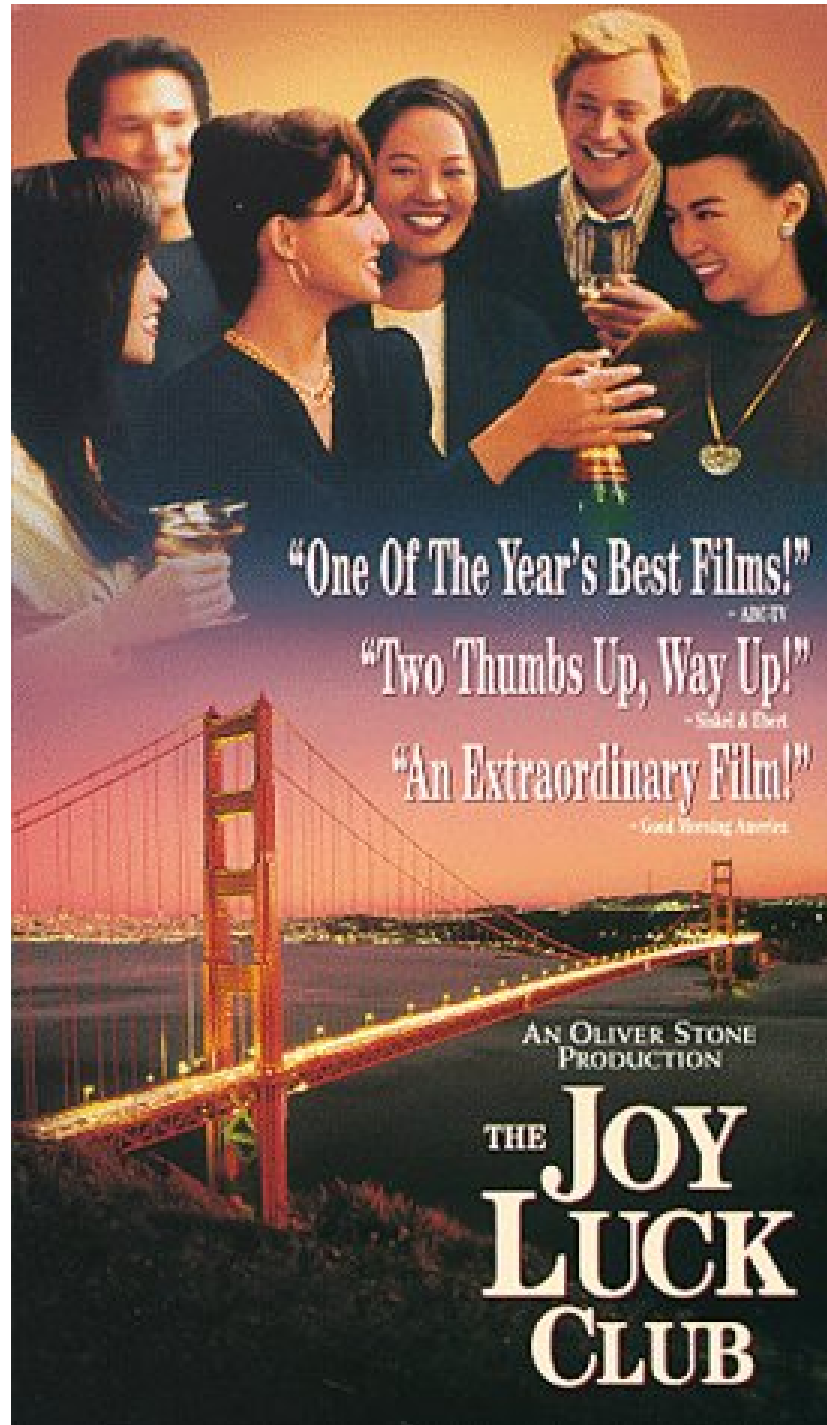




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CBPR: University of Houston Herald Cancer Association





"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

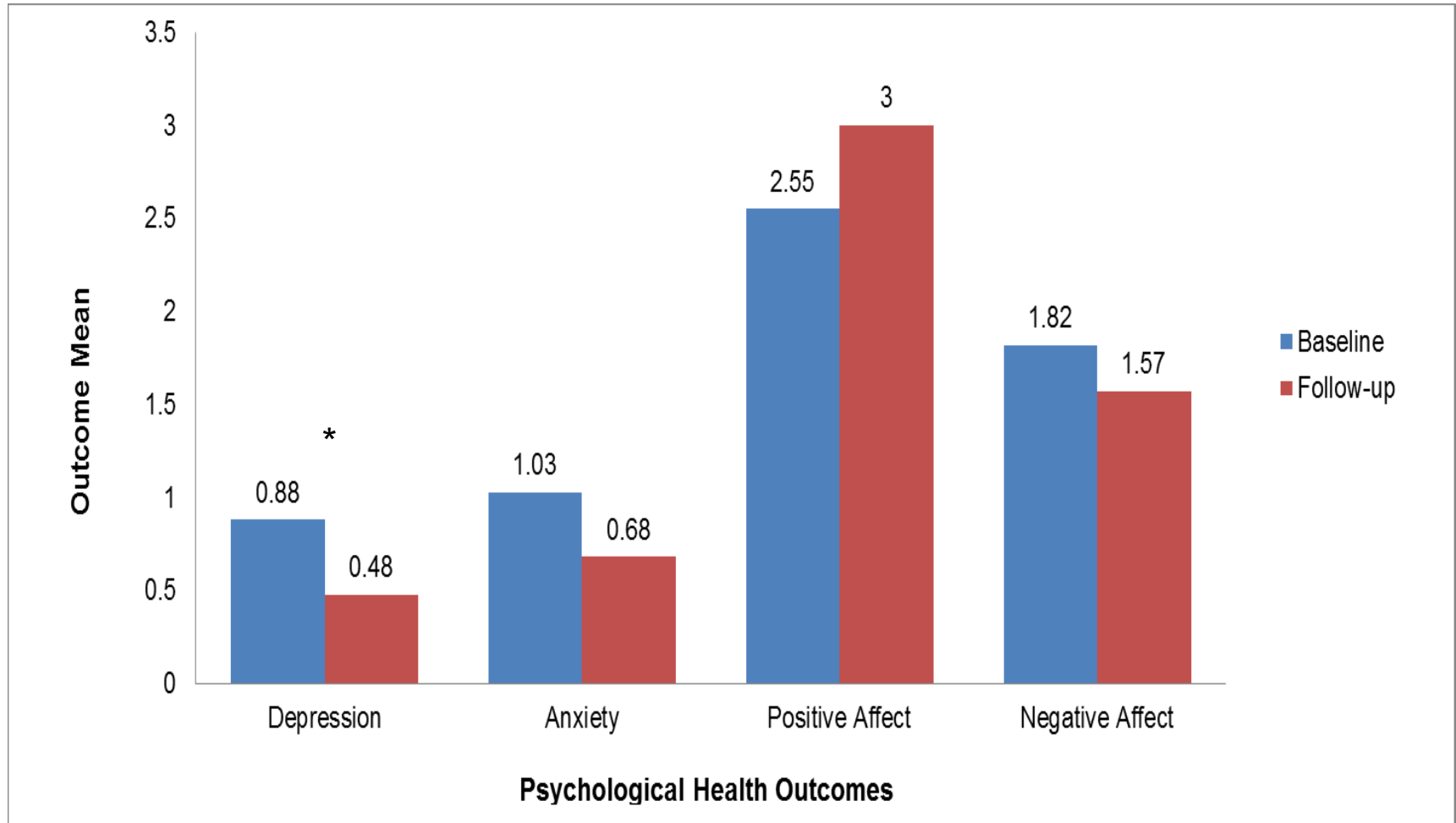
- Education Curriculum

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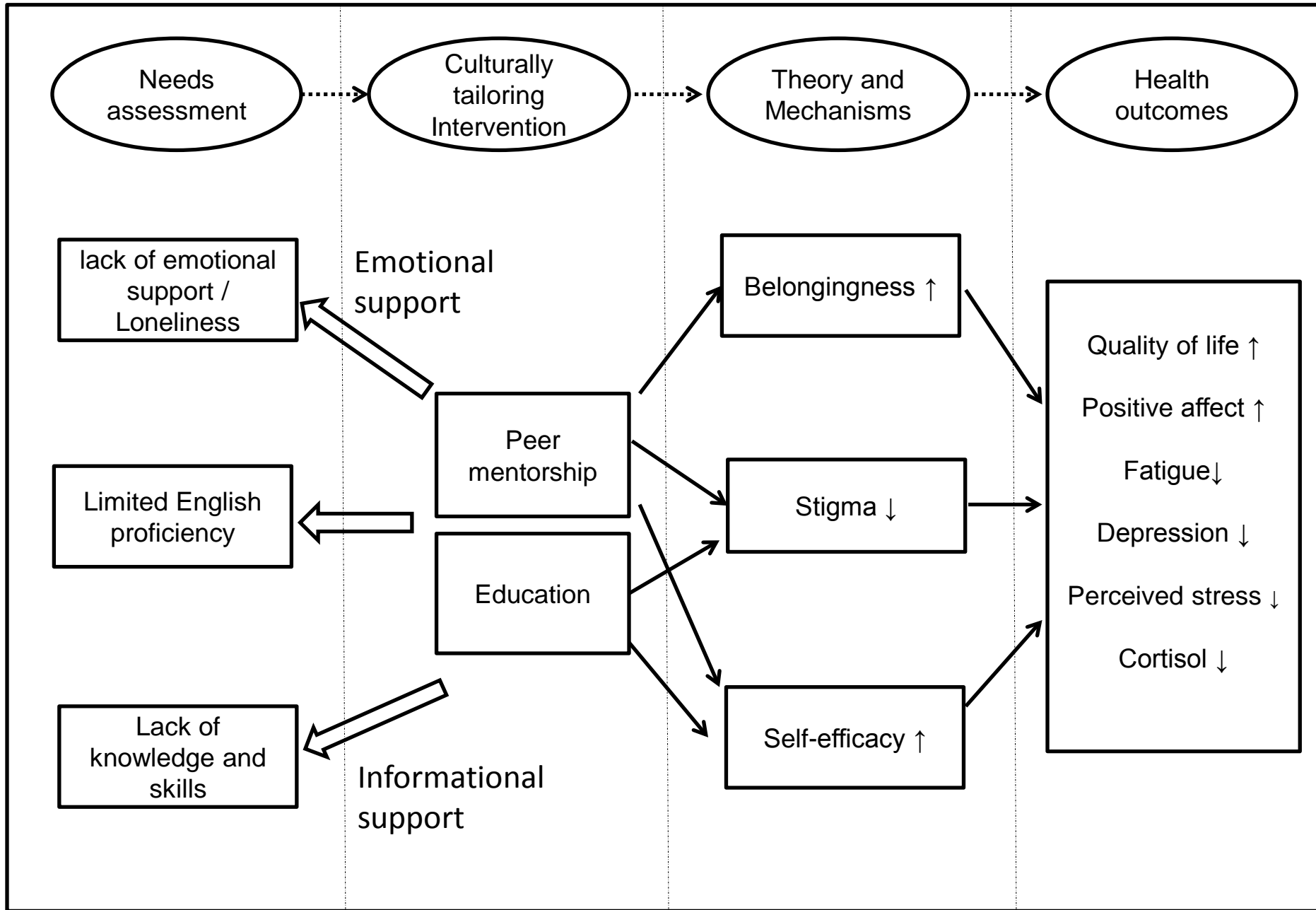
Pilot Study: Outcomes of Joy Luck Academy(JLA) (Lu et al., 2014)



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
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Figure 1 : Joy Luck Academy Intervention Design Rationale



JLA Program

Sharing



JLA Logo

開懷學苑



Lecture



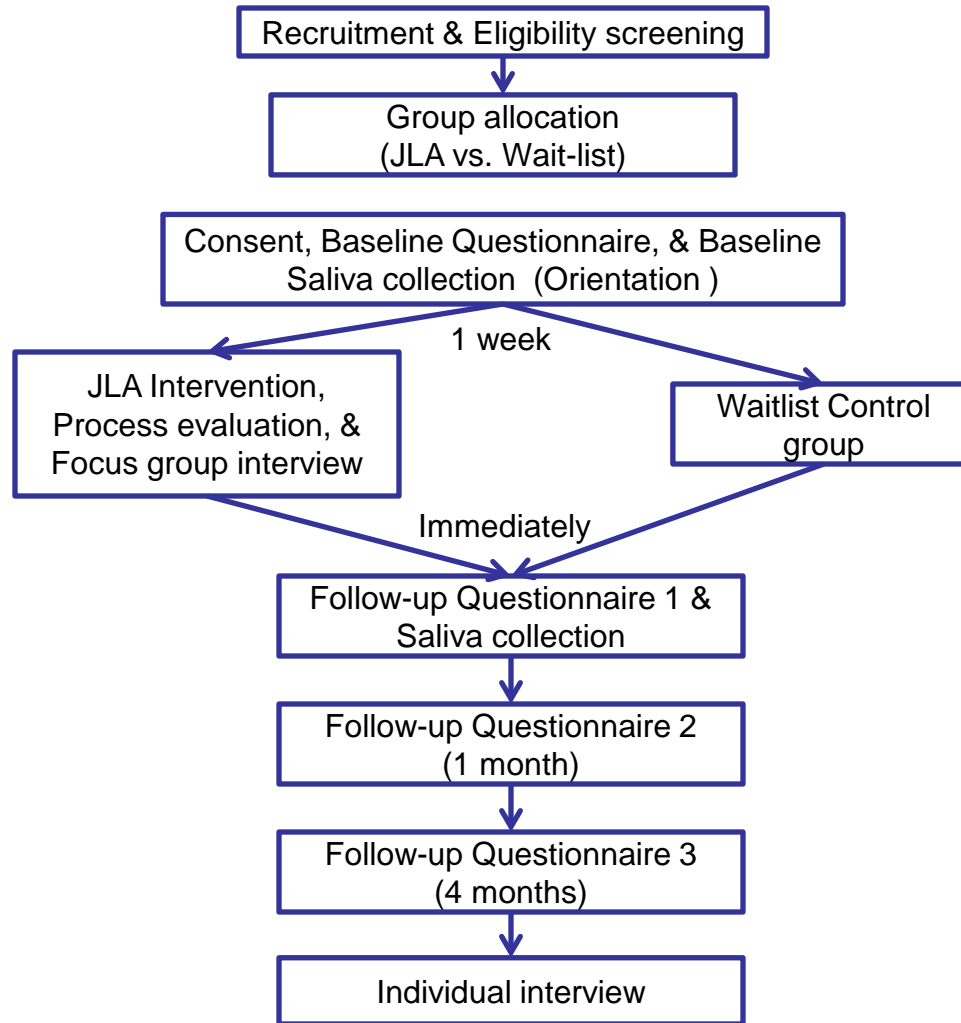
Activities



JLA Mentors



Methods

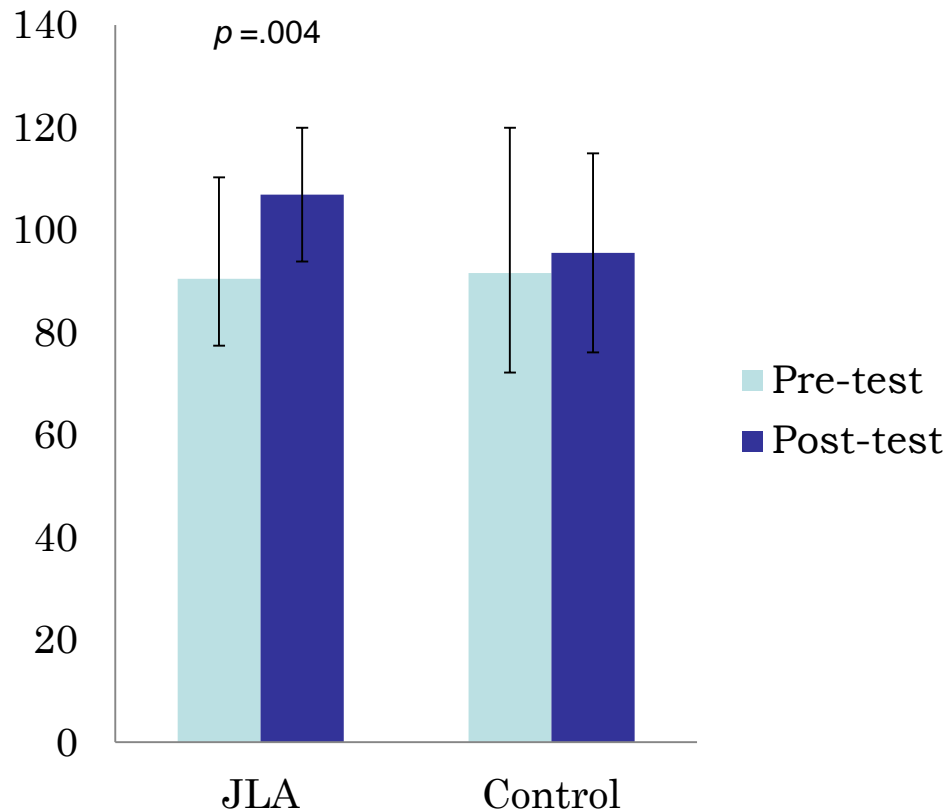


Recruitment and Retention

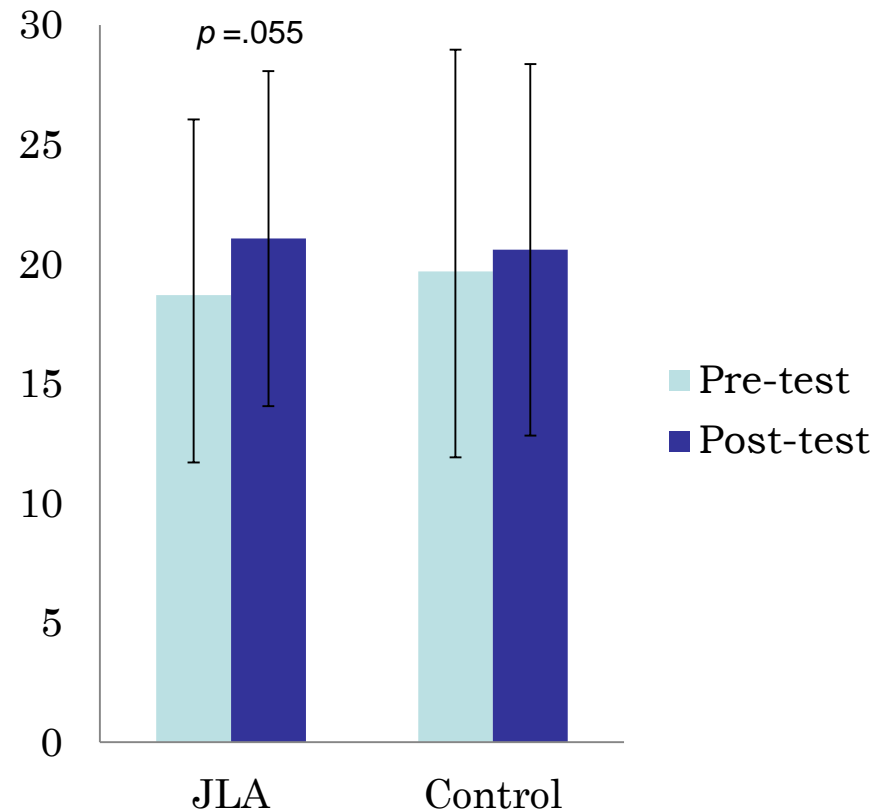
Number of Participants	Cohort 1-JLA	Cohort 2-JLA	JLA total
Recruitment goals	24	24	48
Recruited	19	29	48
Intervention	9	18	27
Control	10	11	21
Dropout	1	0	1
Crossover	None	6	6
Cortisol sample	19		
Follow-up 1(post-test)	18	Ongoing	18
Follow-up 2(1 month)	18	Planning	18
Follow-up 3(4 month)	18	Planning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

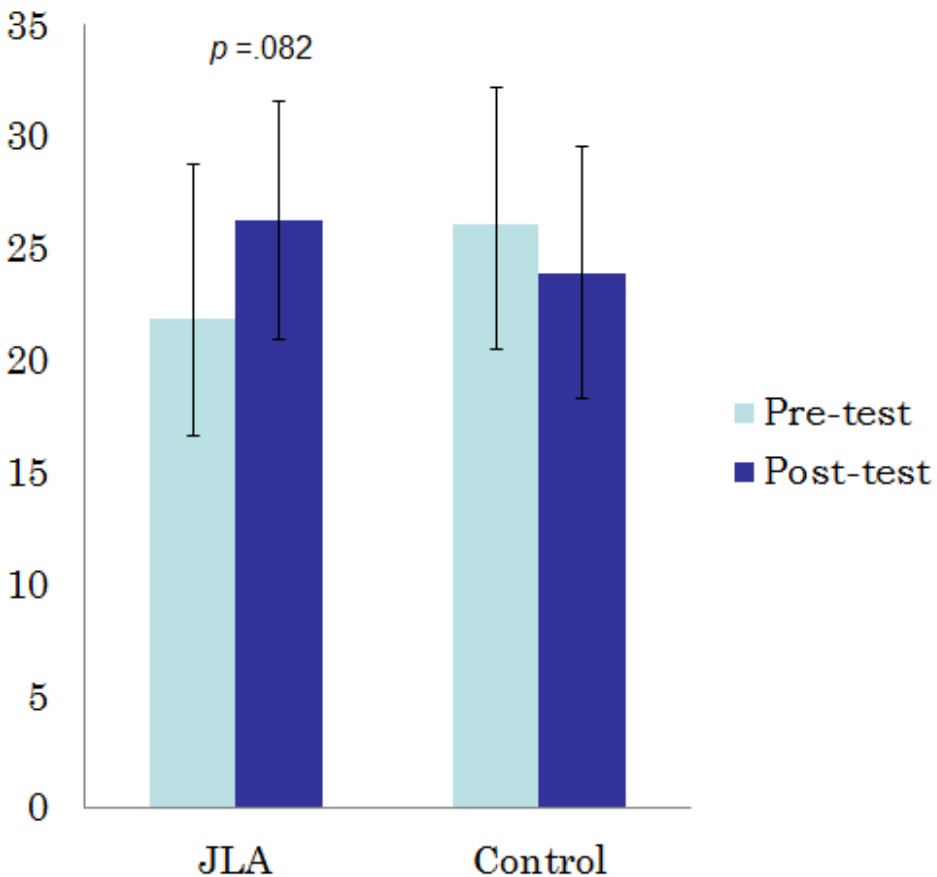


Social QoL

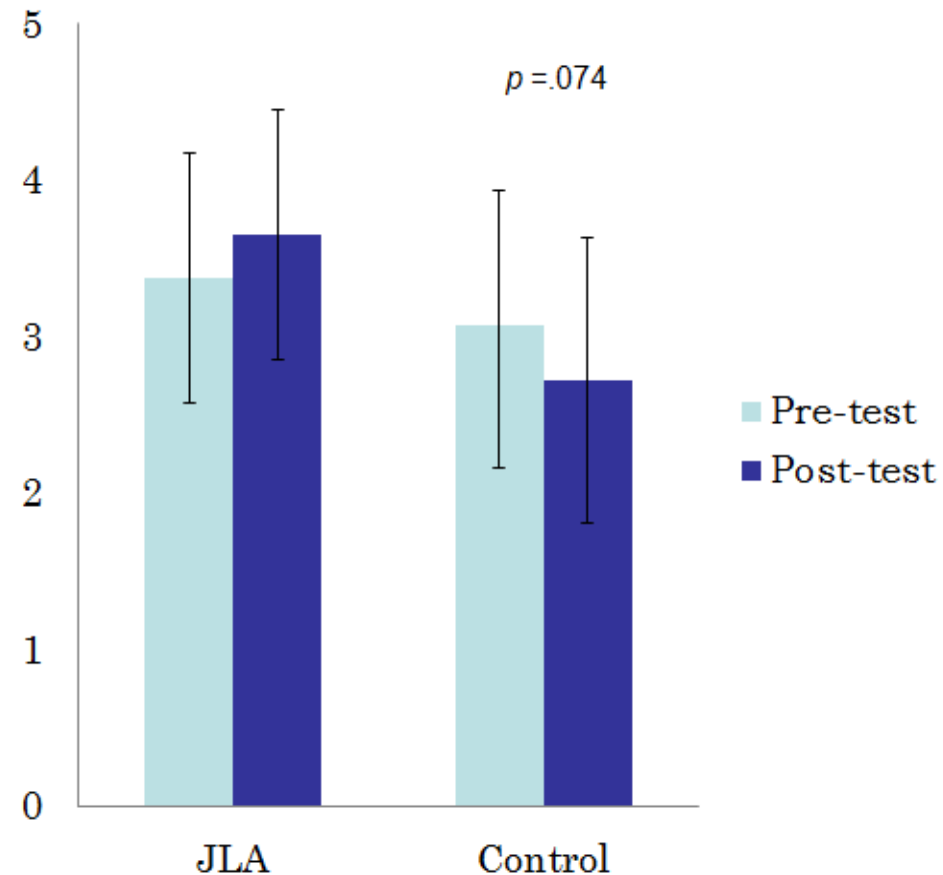


Changes in Health Outcomes (Cohort 1, N=18)

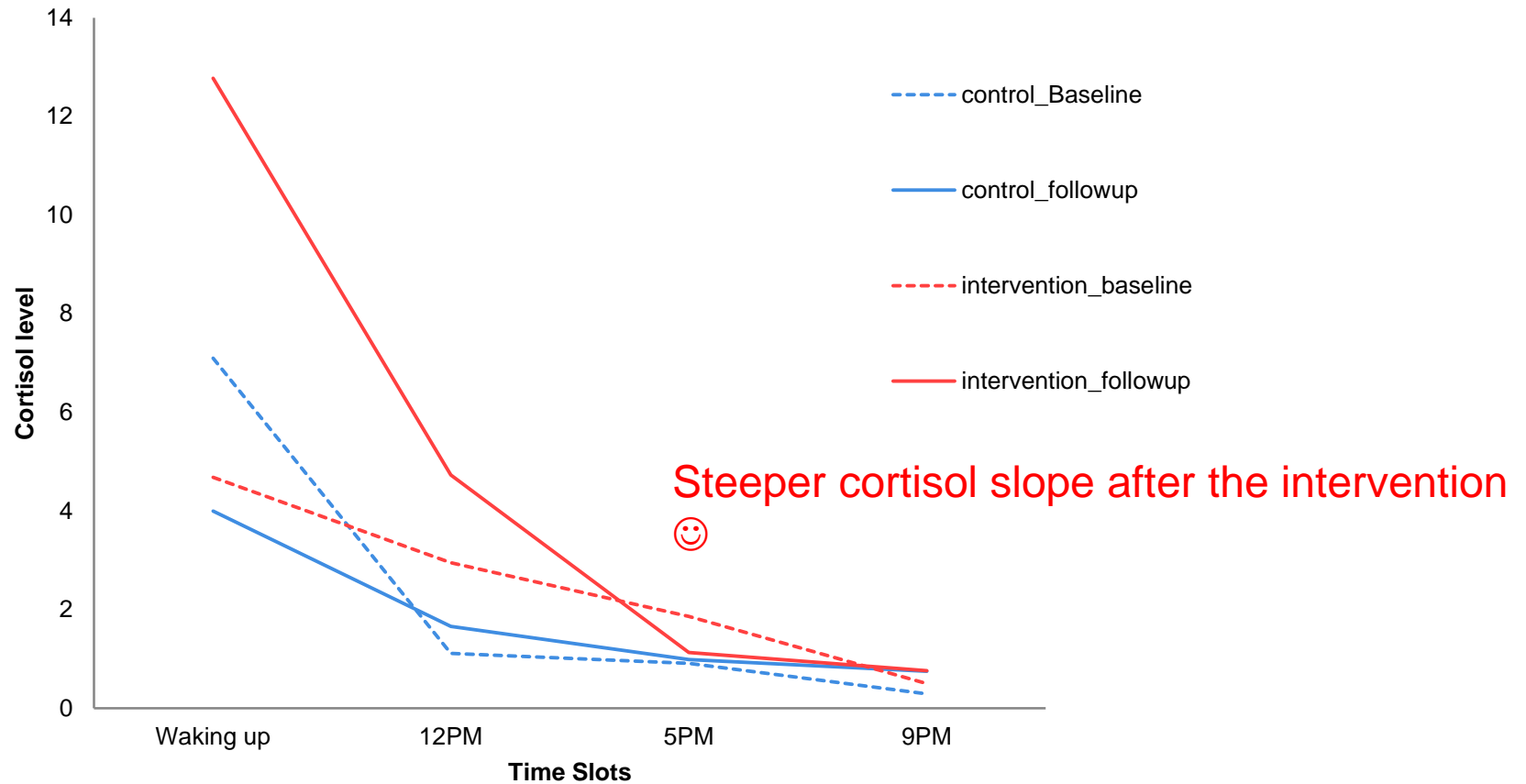
QoL - Additional concerns



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
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Thank you!

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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

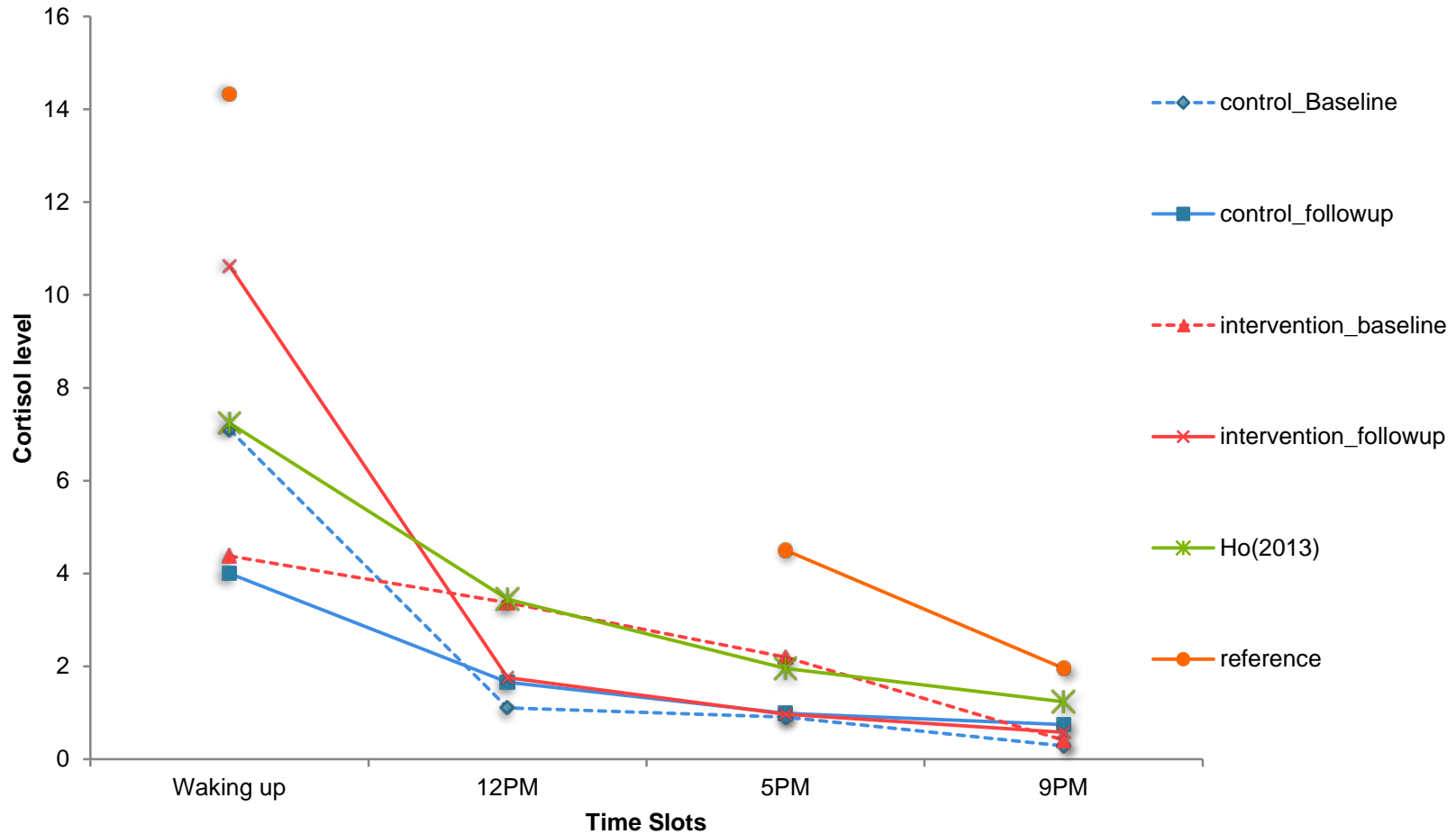
- Calendar
 - Checklists
 - Intervention documentation
 - Participants tracking
- Monitoring: Review
- Session recordings
 - Presentation
 - Study materials
 - Participants tracking
 - Record deviations or modifications to the protocol

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
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