A Life Long Quest in Women's Health through Internet Research Methodology

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Gender and Ethnic Diversities in Health/Illness Experience

- Cancer survivorship (cancer pain management and Internet cancer support groups)
- Midlife women's health issues

A Beginning Question

- A male liver cancer patient with multiple metastases.
  - Why did he suffer to death?
  - What has inhibited him from seeking help for cancer pain management?

Experiential Background

- Oncology staff nurse
- Public health
  - Women's health issues: menopause--ethnic differences in menopausal experience
- International cross-cultural women's health studies--gender and ethnic differences in health/illness experience
- Cancer-related projects with other colleagues—gender and ethnicity-related issues in cancer pain management

Cancer Survivorship

ONF small grant study

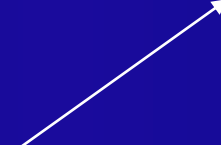RO1 in preparation: ICSGs for AAs

UWM faculty research initiative

Abramson Cancer Center

UWM Graduate School Research Award

RO1 Study: DSCP Study

ONF Outcome Research Grant

Informatics

ONS small grant

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UWM faculty research initiative

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UWM Graduate School Research Award

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ANF-funded Study

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ONF Outcome Research Grant

5 CHPR EPEG funded Studies

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3 Completed RO1 Studies

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Abramson Cancer Center Grant & Pilot Grants

↑

RO1 studies in pending

Program of Research

Informatics

Midlife Women's Health Issues

Oncology Nursing
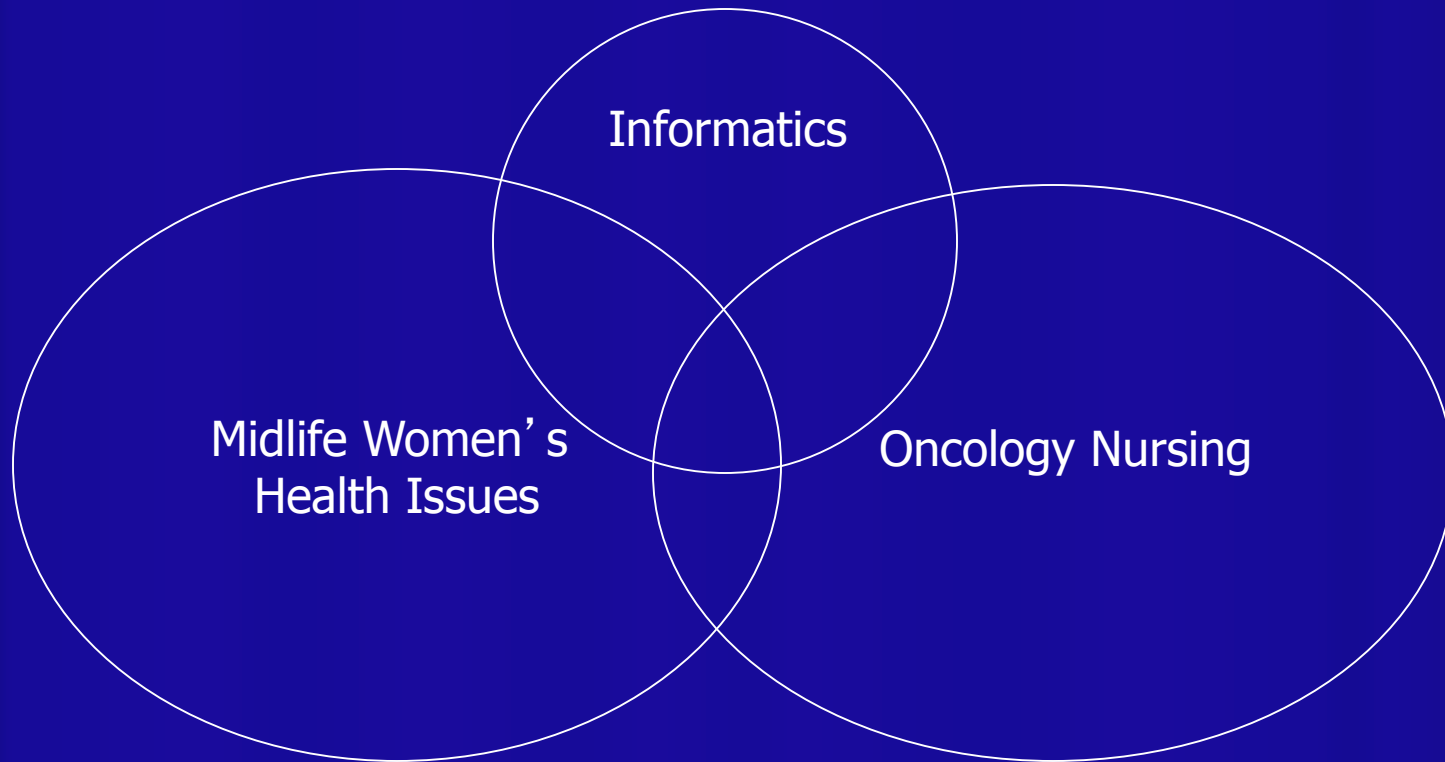
Evolving Research Questions

What are gender and ethnic differences in health/illness experience?

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How could we incorporate the gender and ethnic differences in nursing care?

Theoretical Background/Perspectives

- Feminist Perspective
- Transitions Theory

Feminist Perspective

- To respect women's own experience and own description of their health/illness experience.

- To view gender and ethnicity as significant variables influencing women's health/illness experience.

- To consider psycho-socio-cultural contexts influencing health/illness experience.

Transitions Theory

- Health/illness transition
  - Transitions to cancer survivorship and/or end-of-life quality of life
  - Midlife transition (menopausal transition)
- Situational Transition
  - Cultural transition due to immigration.

Research Methods

- Multi-method approach
  - Quantitative
  - Qualitative
- Internet survey and online forum to reach an adequate number of ethnic minorities residing geographically diverse areas
- Web-based interventions

Feminism-driven Internet research on gender and ethnic differences in health/illness experience

A Multiethnic Internet Study on Menopausal Symptoms (MOMS)

M O M S

A Multiethnic Internet Study On Menopausal Symptoms

Acknowledgement

Background

- Changing racial and ethnic compositions of the U.S. population.
- Significant ethnic differences in menopausal symptom experience episodically reported .
- Rarely focused on multi-ethnic populations in the U.S.
- Few on a national scope with an adequate number of ethnic minorities for a valid comparison.

Purpose

- To explore ethnic differences in menopausal symptom experience among four major ethnic groups in the U.S.

Specific Aims and Research Questions

- **Aim #1**. To explore ethnic differences in menopausal symptom (MS) experience reported by four of the most common ethnic groups of women across the U.S. (Hispanic, White, African American, and Asian)

- <u>RQ1.1</u>. What are the most frequently reported MS, perceived causes of MS, meanings of MS, and management strategies for MS by ethnic group? (Quant)

- <u>RQ1.2.</u> What are ethnic differences in women's self-reported MS? (Quant)

- <u>RQ1.3</u>. What are the qualitative commonalities and dissimilarities in women's self-reported menopausal symptom experience among the four ethnic groups? (Qual)

- **<u>Aim #2</u>**. Explore ethnic-specific contexts of women's daily lives that influence women's self-reported menopausal symptom experience.

- <u>RQ2.1</u>. What are the relationships between contextual factors (sociodemographic characteristics, availability of social supports, smoking status, physical activity, soy consumption, BMI, menopausal status) and women's self-reported menopausal symptoms? (Quant)

- <u>RQ2.2</u>. What are ethnic differences in the contexts within which women describe experiencing menopausal symptoms? (Qual)

Philosophical Basis

- Feminist perspective
  - Ethnicity viewed as a significant factor that influences women's MS experience.
  - The Midlife Women's Symptom Index with a wide range of symptoms used to measure MS.
  - Contextual factors considered as significant factors that influence women's MS experience.

- Women's own experience respected.
- Women's own experience disclosed.
- The distance between the researchers and the women shortened.

Study Design

- A cross-sectional study among midlife women from the four major ethnic groups (Whites, Hispanics, African Americans, and Asians).
  - A quantitative national Internet survey.
  - Four qualitative ethnic-specific online forums.

Settings

- Internet communities/groups for midlife women in the U.S.

- Internet communities/groups for ethnic minorities in the U.S.

Internet Survey Participants

- 512 midlife women
  - 160 Whites, 120 Hispanics, 121 African Americans, and 111 Asians.
- A quota sampling method by ethnicity and socioeconomic status.
- No significant difference in sociodemographic characteristics by ethnicity.

- Inclusion criteria:
  - Middle-aged women between 40 and 60 years old.
  - Those who could read and write English.
  - Those who were online.
  - Those whose self-reported ethnic identity was White, Hispanic, African American, or Asian.

- Sociodemographics:
  - Age: Mean (SD): 48.90 years (5.29)
  - Education: 57% high education (college diploma or above)
  - Religion: 41% Protestants
  - Employment: 73% employed
  - Income: 43% not hard to meet the basics
  - Marital status: 61% married
  - Country of birth: 78% US born

- Smoking: 64% never
- Menopausal status: pre (22%), early peri (31%), late peri (14%), post (33%)
- Diagnosed disease: 58% no
- Hormone usage: 92% no
- BMI: mean (SD): 28.58 (7.97)
- Soy consumption (1=none of the time ~ 4=most of the time): mean (SD): 1.88 (1.00)
- General health (1=very unhealthy ~ 5=very healthy): mean (SD): 3.62 (1.04)

- Level of physical activity (1=much less than other women ~ 5=much more than other women): mean (SD): 2.98 (1.14)
- Social support (1=none of the time ~ 4=most of the time): mean (SD): 2.81 (1.04)

- Sample Size Justification:
  - To address RQ 2.1,
    - 108 research participants per ethnic group (a total of 432) needed with an alpha level of 0.05, a moderate effect size ($R^2 = 0.40$), and a power level of 0.80 with 14 predictors (Borenstein & Cohen, 1988).
  - To address RQ 1.2,
    - 68 participants needed with an effect size of about 0.20 assumed based on the findings of previous cross-cultural studies (Avis et al., 2001; Gold et al., 2000; 2006), an alpha level of 0.05, and power greater than 0.80 (Cohen, 1988).

Online Forum Participants

- 90 self-identified midlife women (23 Whites, 27 Hispanics, 27 African Americans, and 13 Asians) recruited from among the Internet survey participants.

- Convenience sampling method.

- Inclusion criteria: Same to the Internet survey participants.

- Sociodemographics:
  - Age: Mean (SD): 48.90 years (5.29)
  - Education: 84.5% high education (college diploma or above)
  - Religion: 21% Protestants
  - Employment: 80% employed
  - Income: 40% not hard to meet the basics
  - Marital status: 64% married
  - Country of birth: 83% US born

- Menopausal status: pre (9%), early peri (31%), late peri (14%), post (33%)
- BMI: mean (SD): 29.66 (8.56)
- General health: 61% healthy

Instruments

- 14 Questions on background characteristics
  - 14 questions on age, education, religion, marital status, employment, financial status, body weight, height, smoking status, perceived social support, number of close friends/relatives, number of children, level of physical activity, and soy consumption
- 8 Questions on ethnicity-related factors
  - 1 question on self-reported ethnicity, 1 question on country of birth, 1 question on length of stay in the U.S., and 5 questions on level of acculturation

- 10 Questions on health, and menopausal status
  - 1 Likert scale item rating general health and 2 open-ended questions on diagnosed diseases and medicine.
  - 7 items asking about last menstrual cycle, menstrual regularity, and menstrual flow.

- The Midlife Women's Symptom Index
  - 73 items of physical, psychological, and psychosomatic symptoms and an open-ended question about other symptoms (that participants might be experiencing, but not included in the MSI)
  - Severity measures (5-point Likert scales), and open-ended questions on the perceived causes, meanings of, and management strategies for MS.
  - Test-retest correlation, r = 0.94 - 0.98/ Cronbach's alpha=.95
  - Content validity supported by an expert review.

Online Forum Topics

- Language (terminology) used to describe menopause, symptoms, and MS and their linguistic meanings;
- Women's daily life schedules and hardships and sufferings in their daily lives;
- Culturally universal and specific descriptions of MS;
- Women's ethnic-specific attitudes and responses to MS;
- Women's perceived ethnic-specific causes of MS and management strategies for MS;
- Things/life events influencing women's MS experience in their daily lives;
- Women's preferences for symptom management strategies.

Data Collection Procedures

- Development of a website
  - conforming to the Health Insurance Portability and Accountability Act (HIPAA) and the SANS/FBI recommendations.
- Getting informed consents.
- Screening for the inclusion criteria.
- Checking the quota requirement.
- Having the Internet survey.
- Checking consistency of the answers for the purpose of identity verification.

- Getting consents for an additional online forum.
- Conducting online forums.
  - Participants could post messages about the topics at their convenience in any forms they wished (e.g., stories, conversations, responses to others' messages, etc.).
  - The number and length of messages not limited.
    - At least two messages per topic required for reimbursement.
  - The discussions from the online forum summarized monthly and posted on the online forum sites for participants' feedback.

Clients on Internet

Web Browser

Project Website

Internet

Fire Wall

Web Tier

Application Tier

Data/Resource Tier

Network Switch

Apache mod_ssl

JSP/Servlet Environment (Tomcat)

Database Server (PostgreSQL)

Backup System with Tape Backups

Don't be late!!
Keep track of your working time!!

Data Analysis: Internet Survey Data

- Descriptive and inferential statistics
  - Including chi-square tests, ANOVA, hierarchical multiple regression analyses and cluster analyses.

Data Analysis: Online Forum Data

- Descriptive content and thematic analysis (Boyatzis 1998).
  - Line by line coding
  - Categorization
  - Theme extraction
  - Group Discussion

Rigor of the Online Forums

- Dependability
  - By examining the methodological and analytic decision trails created by the investigators during the course of the study itself.

- Reflexivity
  - By maintaining a chronological research diary plus memos and field notes.

- Credibility and relevance:
  - By posting the developing analytic categories on the online forum site and asking for participants' reactions.

- <u>Adequacy:</u>
  - By continuously questioning research methods, goals, research questions, design, scope, analysis, conclusions, and impact of the study within the social and political environment.
- Biweekly research team meetings
  - To ensure the quality of data collection and analysis.

Findings: Internet Survey

RQ 1.1

- The types of the most frequently reported symptoms differed by ethnic identity.
  - The most frequently experienced MS
    - Among Whites, Hispanics, and African: "feeling hot or cold."
    - Among Asians: "decreased sexual interest."
  - Only two top symptoms across all the ethnic groups:
    - "Forgetfulness."
    - "Hot flush" except Asians.

- Only among Whites and African Americans:
  - "Urination at night."
- Only among Whites and Asians:
  - "Muscle and joint stiffness."
- Only among Hispanics and Asians:
  - "Decreased sexual interest."
- Only among Whites:
  - "Weight gain" was not one of the top 10 frequently reported symptoms.

RQ 1.2

- Statistically significant ethnic differences in the **total numbers** of:
  - **Total** symptoms experienced during the menopausal transition ($F=7.98$, $p<0.01$);
  - **Physical** symptoms ($F=8.25$, $p<0.01$);
  - **Psychological** symptoms ($F=7.10$, $p<0.01$); and
  - **Psychosomatic** symptoms ($F=11.20$, $p<0.01$).

RQ 1.2

- Statistically significant ethnic difference in the **total severity scores** of:
  - **Total** symptoms experienced during the menopausal transition ($F=12.71$, $p<0.01$);
  - **Physical** symptoms ($F=13.33$, $p<0.01$);
  - **Psychological** symptoms ($F=7.01$, $p<0.01$); and
  - **Psychosomatic** symptoms ($F=12.64$, $p<0.01$).

RQ 2.1

- <u>Across the ethnic groups</u>, selected contextual factors including **age, employment, income level, ethnicity (being Asians), smoking status, general health status, BMI, and menopausal status** were significant predictors of:
  - **Total number** (R2=.23, p<.01) and
  - **Total severity scores** of symptoms (R2=.26, p<.01).

Predictors	Total		NH White		Hispanic		NH AA		NH Asian	
	ß	p-value	ß	p-value	ß	p-value	ß	p-value	ß	p-value
Intercept	46.3441	<.0001	75.2984	<.0001	-7.2716	<.0001	12.2089	.1171	11.1895	.2303
Age	-0.4811	.0002	-0.5850	.0062	--	--	--	--		
Employment (yes/no)	3.6468	.0088			12.5130	<.0001	--	--	--	--
Income level	-2.8024	.0010	-6.1240	<.0001	--	--	-4.8503	.0045	--	--
Ethnicity (being Asians)	-5.5663	.0004	--	--	--	--	--	--	--	--
Country of birth (US or not)	--	--	--	--	--	--	--	--	--	--
Level of acculturation	--	--	--	--	--	--	--	--	0.4039	.0322
Level of physical activity	--	--	--	--	--	--	--	--	-0.5891	.0048
General health	-1.8425	.0031	-3.6387	.0003	--	--	--	--		
BMI	0.2726	.0007	--	--	0.5988	.0006	0.4183	.0027	--	--
Menopausal status	1.3913	.0161	2.2962	.0175	--	--	--	--		
R^2	0.2261		0.3494		0.2275		0.1531		0.1544	
F	16.30		16.54		8.47		7.05		4.84	
p-value	<.0001		<.0001		<.0001		.0002		.0013	

- Among Whites, age, income level, general health status, and menopausal status were significant predictors of the total **number** of total symptoms ($R^2=.35$, $p<0.01$).

- Among Hispanics, employment and BMI were significant predictors of it ($R^2=.23$, $p<0.01$).

- Among African Americans, income level and BMI were significant predictors of it ($R^2=.15$, $p<0.01$).

- Among Asians, the level of acculturation and the level of physical activity were significant predictors of it. ($R^2=.15$, $p<0.01$).

Predictors	Total		NH White		Hispanic		NH AA		NH Asian	
	β	p-value	β	p-value	β	p-value	β	p-value	β	p-value
Intercept	163.8997	<.0001	272.3870	<.0001	-26.8440	.4533	32.1302	.2524	21.5010	.4934
Age	-1.7170	.0002	-1.9300	.0144	--	--	--	--		
Employment (yes/no)	15.0651	.0026	--	--	49.7398	<.0001	--	--	--	--
Income	-13.4706	<.0001	-25.5444	<.0001	--	--	-21.9920	.0003	--	--
Ethnicity (being Asians)	-19.5831	.0005	--	--	--	--	--	--	--	--
Country of birth (US or not)	--	--	--	--	--	--	--	--	--	--
Smoking (yes/no)	13.4433	.0352	--	--	--	--	--	--	--	--
Level of physical activity	--	--	--	--	--	--	--	--	-1.8900	.0072
General health	-7.8237	.0005	-14.8935	<.0001	--	--	--	---	--	--
BMI	1.0104	.0005	10.5996	.0032	2.3436	.0002	1.4229	.0037	--	--
Menopausal status	5.8761	.0046	--	--	--	--	--	--	--	--
R^2	0.2659		0.4237		0.2731		0.2192		0.1555	
F	18.15		18.75		8.57		6.46		4.88	
p-value	<.0001		<.0001		<.0001		<.0001		.0012	

- Among Whites, age, income level, general health status, and BMI were significant predictors of the total **severity** of total symptoms ($R^2 = .42$, $p < 0.01$).

- Among Hispanics, employment and BMI were significant predictors ($R^2 = .27$, $p < 0.01$).

- Among African Americans, income level and BMI were significant predictors ($R^2 = .22$, $p < 0.01$).

- Among Asians, only the level of physical activity was a significant predictor ($R^2 = .16$, $p < 0.01$).

- After comparing the menopause symptoms scores, the three cluster solution adopted for this study ($F=575.71$, $p<.01$).
  - Cluster 1 (the low symptomatic group): 274 women (47%)
  - Cluster 2 (moderate physical and psychosomatic, high psychological, and low menstrual symptoms): 148 women (29%)
  - Cluster 3 (the high symptomatic group); 79 women (15%)
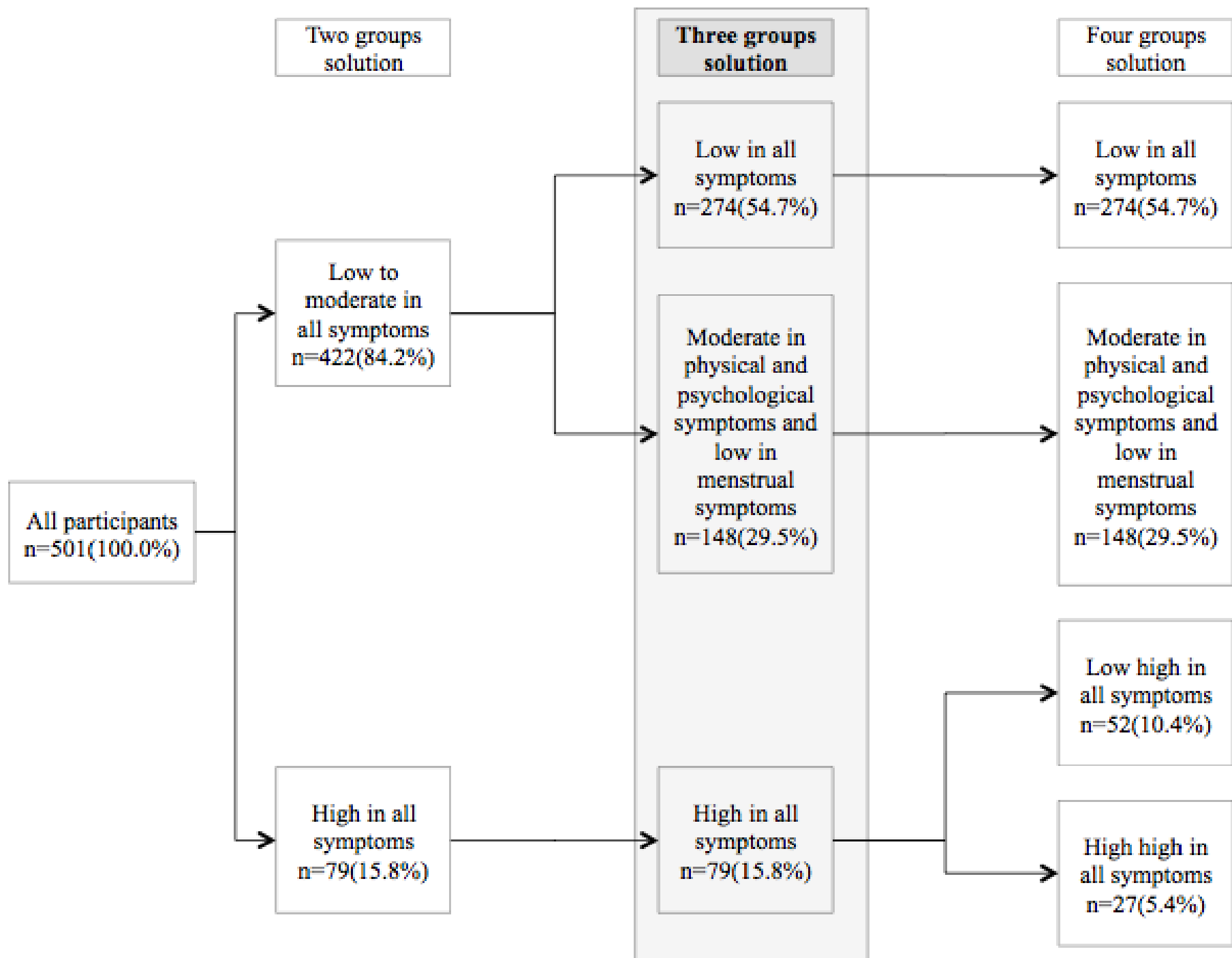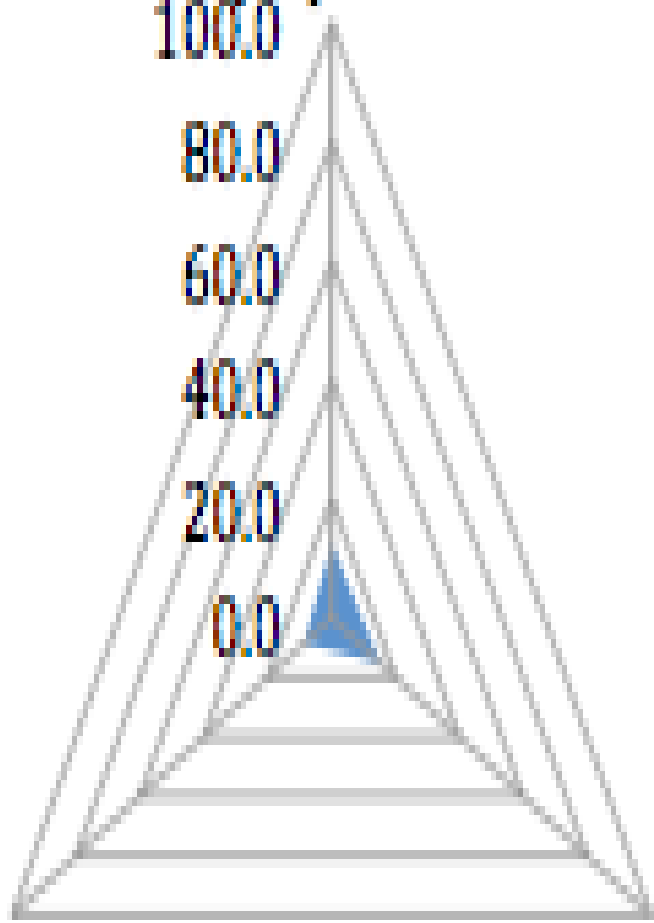
Physical-psychosomatic symptoms

100.0
80.0
60.0
40.0
20.0
0.0

Menstrual symptoms

Psychological symptoms

■ Cluster1

Physical-
psychosomatic
symptoms

100.0

80.0

60.0

40.0

20.0

0.0

Menstrual
symptoms

Psychological
symptoms
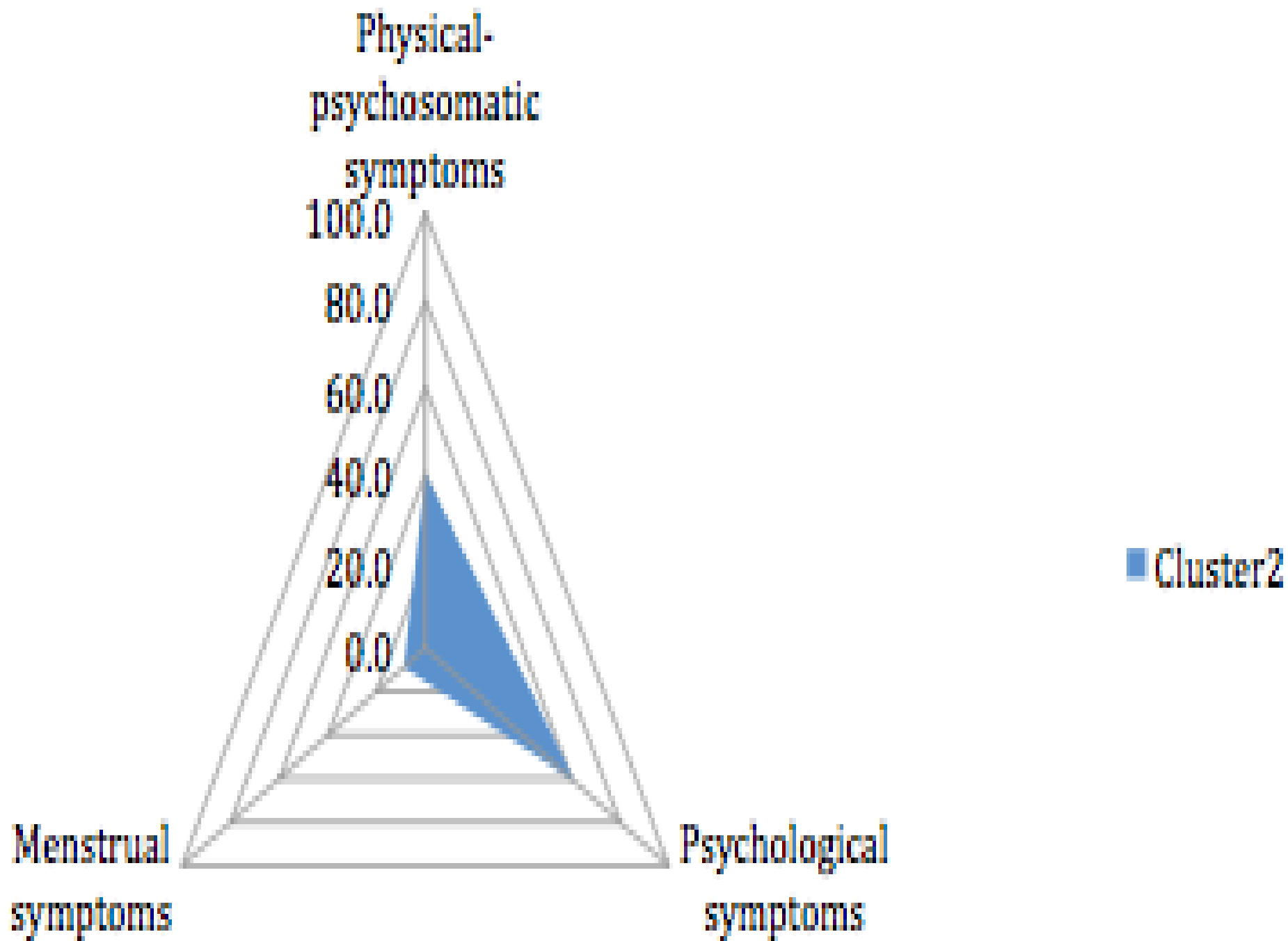
■ Cluster2

Physical-
psychosomatic
symptoms

100.0
90.0
80.0
70.0
60.0
50.0
40.0
30.0
20.0
10.0
0.0

Menstrual
symptoms

Psychological
symptoms

■ Cluster 3
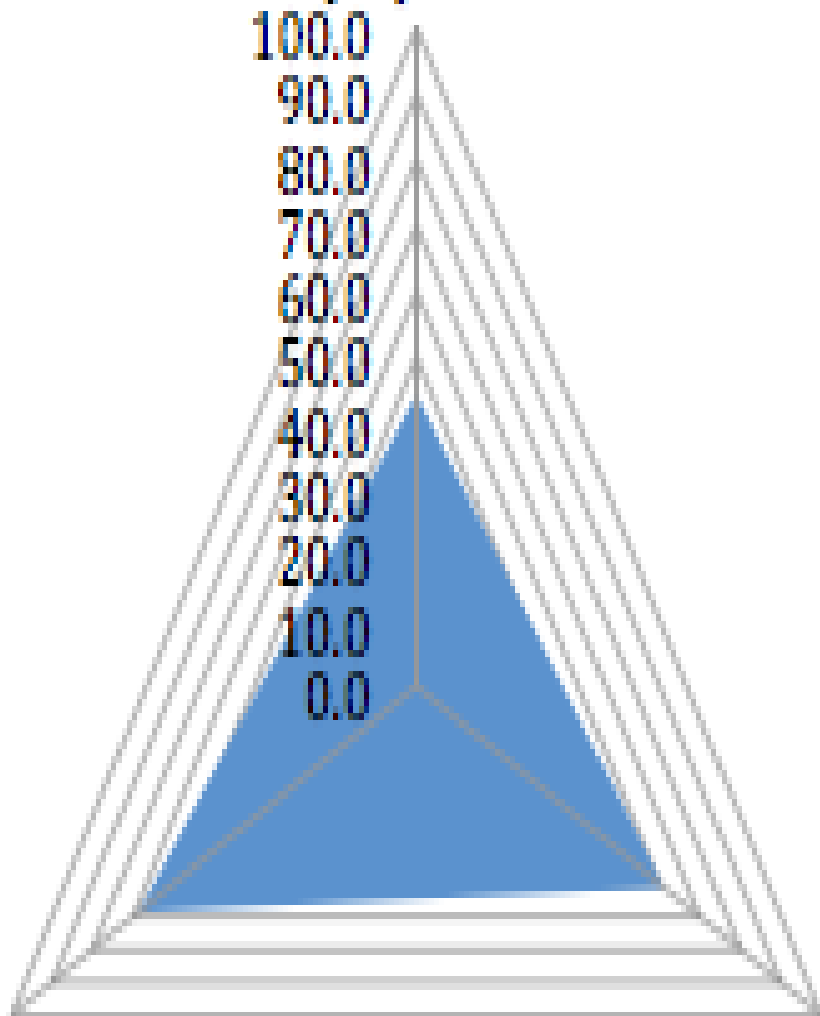
- The three clusters differed significantly in **age, education level, income, number of children, country of birth, ethnicity, BMI, self-reported health, diagnosed disease, smoking, and physical activity** ($p<.05$).

- **Only in Cluster 1**, there were **significant ethnic difference**s in the scores of total symptoms and physical and psychosomatic symptoms, and in 7 individual symptoms
  - White & African American > other ethnic groups: 'night sweat', 'hot flush', 'feeling hot or cold', 'swelling ankles', 'breast pain' and 'feeling clumsy.'
  - Hispanic > other ethnic groups: 'crying often.'

- **No ethnic difference** in the scores of total symptoms and subcategories of symptoms in **cluster 2.**
- Significant differences in **individual** symptoms in **cluster 2.**
  - Whites >: 'palpitation' and 'frequent loose stools'.
  - White & Hispanic >: 'severe headache', 'feel clumsy' and 'aches in the back of neck and skull'.
  - White &Asian >: 'muscle and joint stiffness and soreness;'
  - White & African American >: 'night sweat.'
  - Asian < : 'hot flush.'
  - White & Asian American >: 'feeling anxious, tense or nervous frequently', 'worrying', 'feeling panic frequently.'

Findings: Online Forums RQ1.3 & 2.2

Findings: Commonalities
"Just a Part of Life"

- "I usually call period[s] 'that time of the month' or 'women troubles'. As for menopause I usually just refer to it as 'the changes' since I guess that is what it really is. Funny how when reading some of the other posts it occurs to me yet again that something that is natural and part of our development as women is usually referred to in 'abnormal' or troublesome type of terms." (White)

- "The change of life which I have always heard it been called in Hispanic culture is like entering a new phase in your life. Your body is going through changes, irregularity or end of periods, and your way of thinking changes." (Hispanic)

"Trying to be Optimistic"

- "I feel that we…should be embracing this new part of our life and see where it leads us instead of focusing on the negative aspects of this. If we look back at our life…we…had changes and we dealt with them and continued on to become mature women."(White)

- "Menopausal symptoms aren't exactly enjoyable but everything in life is about growth and learning. If we keep that in mind than focus on discomfort, the journey is much more fulfilling." (Asian)

"Getting Support"

- "I don't like the changes my body is going through…but I feel that there is nothing I can do about it and every woman is going to experience these changes…My family and friends are very supportive of me and usually try to make me feel more comfortable by doing errands for me while I take a nap which really makes me feel a lot better." (White)

- "Fortunately I'm in a phase of life with the age of the last kid in the house and with my husband having grown more attuned to my needs, where I finally feel entitled enough to ask for help when I need it. They made dinner without making me feel guilty, and my husband rubbed my back…It made me feel appreciated and loved." (African American)

"More Information Needed"

- "I'd like to say that WebMD is a great source of information for any ailment of medical issue. I also don't hesitate to ask the doctor lots of questions when I'm there. And when all else fails, I ask my family and friends what helps them get through…"(Hispanic)

- "Because of the information age we live in, and the openness of society today, one way that I deal with my problems and discomfort and frustrating symptoms, is to search for solutions and read experiences of folks." (Asian)

Findings: Differences
"Open and Closed"

- "I think we deal with it very openly, I was just going through a local magazine today listing activities and amusements in our area and one of them was a theater production called "Menopause the musical". It really struck me as funny. Menopause is now discussed in TV ads, many magazines are dealing with help tips on how to deal with menopause, as was said before it's much more open now." (White)

- "In my specific culture we are taught as Black women to survive, no matter how you feel, so menopausal symptoms were not really discussed until my sisters and I reached that point in our lives when we started having the symptoms ourselves." (African American).

"Universal and Unique"

- "I think that the symptoms are pretty much the same for everyone no matter what ethnic group or race you are. What's inside a woman's body is pretty much the same as every other woman." (White)

- "In my culture we are used to just getting along and not complaining a lot about natural things like pregnancy, menopause, etc. Like in the western world there are terms like post-partum depression etc., these terms are unheard of in my culture. We just have to get along and take things in our stride instead of making a big deal out of it." (Asian)

"Controlling and Minimizing"

- "I went running to my General Practitioner when my symptoms first started…She calmed me down a little and referred me to an OBGYN. He diagnosed my "disorder" as menopause and discussed it with me at length. He said we may consider HRT at some future date…I prefer relaxation therapy and acetaminophen…"(White)

- "As African American women, we are always expected to be strong women who aren't supposed to whine about anything. You just take life as it comes and do what you have to do. If you are having troubles or problems, you should just pray about it and keep going. I don't think that my culture believes that menopausal symptoms are something that you would have to run to the doctor." (African American)

Discussion

Discussion:
Internet Survey Findings

- Significant ethnic differences in menopausal symptoms
  - Agree with some existing studies (Gold et al., 2000; National Health and Nutrition Examination Survey [NHANES], 2003).

- Differences in the most frequently reported symptoms by self-reported ethnic identity.
  - Reaffirm findings in the literature (Ho et al., 2003; Haines et al., 2005).

- Ethnicity as a significant predictor of the total number or severity of symptoms across ethnic groups

- Level of acculturation as a significant predictor of the total number of total symptoms among N-H Asian women.

  - Agree with previous studies (Green & Santoro, 2009; Thurston et al., 2008a; 2008b; Appling, Paez, & Allen, 2007; Gold et al., 2006).

- Significant associations of sociodemographic status, lifestyle, and health-related contextual factors with menopausal symptoms
  - Agree with existing studies (Brzyski et al., 2001Gold, 2000; 2006; Ho et al., 2003).

➔These findings confirm those from small scale existing studies.

Discussion:
Online Forum Findings

- "*Just a part of life*" and "*Trying to be optimistic*"

  - **<u>Frequently</u>** reported in **<u>ethnic minorities</u>** (Im & Meleis, 2000; Lock, Kaufert, & Gilbert, 1988; Sampselle et al., 2002; Villarruel, Harlow, Lopez, & Sowers, 2002).

  - **<u>Rarely</u>** reported in **<u>White women.</u>**

- "Getting support"
  - **Frequently** reported in **White** women (Sampselle et al., 2002).
  - **Rarely** reported in **ethnic minority women** (Grisso, Freeman, Maurin, Garcia-Espana, & Berlin, 1999; Im & Meleis, 2000; Lock et al., 1988).

- "Controlling and minimizing"
  - **<u>Agree with the literature</u>**
    - <u>Ethnic minorities</u> tend to manage their symptoms by tolerating, ignoring, normalizing, and minimizing (Cooper & Barthalow, 2007; Grisso et al., 1999; Strickland & Dunbar, 2000)
    - <u>White women</u> tend to adopt diverse management strategies for MS (Brett & Cooper 2003; Whiteman, Staropoli, Benedict, Borgeest, & Flaws, 2003).

- "Open and closed"
  - More positive than previous findings.
- "Universal and unique"
  - A new finding.

➔This may mean a positive change in White women's and ethnic minority women's attitudes toward menopause and MS.

Limitations

- A selected group of midlife women
  - Sub-ethnic compositions of each ethnic group not representing all the diverse ethnic subgroups within each major ethnic group.
- Limitations due to the inherent nature of Internet research

Implications

- Need to consider ethnic differences in symptoms experienced during the menopausal transition in their health care practice and research projects.
  - Further studies needed for ethnic differences in **symptom clusters** and **specific individual symptoms**.

- Need to consider these **<u>recent positive changes</u>** in women's attitudes toward menopause and MS in their health care practices and research projects.

- Need to develop and/or test **<u>educational programs</u>** that provide information and knowledge on menopause and MS.

The Recently Completed R01 Study

- eMAPA study (Ethnic-Specific Midlife Women's Attitudes toward Physical Activity): funded by NIH/NINR/NHLBI (1R01NR010568-01), 2007-2013.

Ongoing Pilot Studies

- Internet Cancer Support Group for Asian Americans
  - Funded by The Population Science Pilot Project Award, The NCI Cancer Center Support Grant (P30 CA016520) and the Abramson Cancer Center of the University of Pennsylvania
- Web-based physical activity promotion program for Asian Americans
  - Funded by the Honorary President's Grant from Chang Gung University of Science and Technology, Taiwan

Future Directions???