

ABSTRACT

Title of Thesis: A FEMINIST PERSPECTIVE ON
COPING WITH INTERPERSONAL
STRESS IN CHRONIC DISEASE

Elizabeth Reeves, Master of Arts, 2017

Thesis directed by: Professor Mary Ann Hoffman, Ph.D.
Counseling, Higher Education and
Special Education

The present study used a feminist framework to better understand how women with chronic disease cope with interpersonal, disease-related stressors. Specifically, it examined how gender-related stress, including traits (e.g., unmitigated communion) and relationship schemas (e.g., self-silencing) impact adjustment among women with Celiac Disease, and whether gendered coping processes, such as emotional approach coping, play a mediating or moderating role. Data was collected from 344 women with Celiac Disease through an online survey. Results demonstrate the importance of gender-related stress for psychological adjustment to CD among women. Findings suggest that although emotional approach coping may be a beneficial strategy when managing disease-related interpersonal stress, other forms of coping requiring interpersonal agency may be more important. Future research should investigate relationships between gender-related stress and problem-focused coping while considering the influence of disease-related factors such as time since diagnosis, symptom severity and symptom frequency.

A FEMINIST PERSPECTIVE ON COPING WITH INTERPERSONAL
STRESS IN CHRONIC DISEASE

by

Elizabeth Reeves

Thesis submitted to the Faculty of the Graduate School of the
University of Maryland, College Park in partial fulfillment
of the requirements for the degree of
Master of Arts
2017

Advisory Committee:
Professor Mary Ann Hoffman, Chair
Associate Professor Paul Gold
Associate Professor Jonathan Mohr

© Copyright by
Elizabeth Reeves
2017

Table of Contents

List of tables.....	ii
List of figures.....	iii
Chapter 1: Introduction.....	1
Chapter 2: Statement of the Problem.....	10
Hypotheses.....	11
Chapter 3: Methods.....	15
Chapter 4: Results.....	26
Chapter 5: Discussion.....	43
Appendix A: Review of Literature.....	63
Appendix B: Recruitment Documents and Informed Consent.....	89
Appendix C: Eligibility Criteria and Demographic Questionnaire.....	95
Appendix D: Interpersonal Stress Survey.....	98
Appendix E: Emotional Approach Coping Scale.....	99
Appendix F: Social Receptivity Scale.....	100
Appendix G: Silencing the Self Scale.....	101
Appendix H: Revised-Unmitigated Communion Scale.....	103
Appendix I: Brief Symptom Inventory.....	104
Appendix J: Celiac Disease-Quality of Life Scale.....	105
References.....	106

List of Tables

Table 1.....	17
Table 2.....	27
Table 3.....	30
Table 4	32
Table 5.....	33
Table 6.....	34
Table 7.....	35
Table 8.....	36
Table 9.....	37
Table 10.....	38
Table 11.....	39
Table 12.....	41
Table 13.....	42

List of Figures

Figure 1.....11

Chapter 1: Introduction

As of 2012, about half of all adults (117 million people) have one or more chronic health condition (Ward, Schiller, & Goodman, 2014). Chronic illness yields negative psychological and social consequences that are associated with greater distress and poorer quality of life (e.g., Ciaramella & Poli, 2001; Dickens, Chris, Linda, Clark-Carter, & Creed, 2002). While adjustment varies greatly across individuals, research shows that women report significantly more difficulty with pain, symptoms, disability and psychological health than do men (e.g., Chapman, Perry, & Strine, 2004; Katz & Criswell, 1996; Keller & Henrich, 1999). Relative to men, women with chronic illnesses have a greater vulnerability to and prevalence of depressive disorders, higher levels of disease-related distress, lower levels of life satisfaction, and poorer quality of life (Chapman et al., 2004; Katz et al., 2003; Keller & Henrich, 1999; Simrén, Abrahamsson, Svedlund, & Björnsson, 2001).

Gender is known to play a significant role in many aspects of stress and coping processes (Annette L. Stanton, Revenson, & Tennen, 2007). In general, women report experiencing stressors more frequently and with greater severity than do men (L. K. J., Denise Helgeson, Vicki S. Tamres, 2002). Importantly, women also report experiencing more interpersonal stressors, or those involving relationships and social networks, than do men (Helgeson, 2010). This may be particularly relevant to disease adjustment, when most adaptive tasks require help from others, including emotional sustenance and practical aid. Just as relationships and social networks can be supportive and caring in response to one's illness, they also can be characterized by misunderstanding, disapproval and antagonism (Stanton, Revenson & Tennen, 2007). For women with

FEMINIST PERSPECTIVE CHRONIC DISEASE

illnesses that greatly interfere with social activities, greater sensitivity to interpersonal stressors may make psychological adjustment especially challenging.

Multiple feminist theories explain why women are particularly vulnerable to stressors involving relationships and social networks. These theories postulate that communion and mutual relationships are central tenants of female development and that women may sacrifice themselves and their own needs when threats to connection or mutual relationships are present. Given that chronic illness often strains relationships, these theories may provide a useful framework for understanding women's greater difficulty with adjustment. Thus, the present study seeks to understand relationships between the stress associated with maintaining connection and relationships (gender-related stress), psychological distress and disease-related quality of life. Specifically, it seeks to understand how gender-related stress might interact with disease-related interpersonal stress to predict use of an adaptive, socially dependent coping strategy, emotional approach coping.

Theory of Unmitigated Communion

One theory that might help to better understand the negative impact of gender-related stress on disease adjustment is that of unmitigated communion. Unmitigated communion theory stems from traditional definitions of the female gender role as one striving for interpersonal connection (J. Spence, 1984). Although a communal orientation is associated with positive, mutual relationships, it is also associated with a risk for developing unmitigated communion (UC; Helgeson & Fritz, 1999). UC is a personality orientation that is defined as a focus on others to the exclusion of the self, placing others' needs before one's own (Helgeson & Fritz, 1999). It is associated with lower self-esteem,

FEMINIST PERSPECTIVE CHRONIC DISEASE

over involvement with others and self-neglect. Individuals who score higher on measures of UC base perceptions of themselves on others' view of them, which leads them to fear negative evaluation by others. They are overly nurturing, intrusive and self-sacrificing and they may provide support to others to enhance self-worth (Helgeson, 1998). Women with higher levels of UC have difficulty asserting themselves and may even experience discomfort receiving support or engaging in self-disclosure (Fritz & Helgeson, 1998). Not surprisingly, scores on measures of this gender-related trait are higher in women than in men and are associated with greater sensitivity to interpersonal stressors (Nagurney, 2007; Reynolds et al., 2006) as well as anxiety and depressive symptoms in community samples (e.g., Fritz & Helgeson, 1998).

A large body of literature demonstrates that the combination of over-involvement with others and failure to attend to one's own needs is associated with poorer adjustment to chronic disease. Higher levels of UC predict anxiety and depression symptoms in adolescents with diabetes and adults with cardiac disease, rheumatoid arthritis, breast cancer and HIV (Brody et al., 2014a; Helgeson, 2003; Helgeson & Fritz, 1999; Trudeau, Dannoff-Burg, Revenson, & Paget, 2003). UC has significant interpersonal implications for female patients across medical conditions: it has been linked to lower levels of self-advocacy (HIV; Brody et al., 2014a), more negative social interactions (cardiac disease, breast cancer; Fritz, 2000; Helgeson, 2003) and more negative affect in response to relationship stress (diabetes and fibromyalgia; Helgeson & Fritz, 1996; Nagurney, 2008). Interpersonal stress associated with UC may even affect specific health outcomes. In one study of adolescents with diabetes, Helgeson and Palladino (2012) found that UC predicted poorer relationship quality and that this mediated the relationship between UC

FEMINIST PERSPECTIVE CHRONIC DISEASE

and poorer metabolic control. In sum, research shows that the stress associated with an excessive focus on others might interfere with one's ability to manage aspects of one's own health and that this may negatively impact disease adjustment. Additional research is needed, however, to understand the role of UC on disease-related interpersonal stress more specifically. Although the current literature has drawn connections between higher levels of UC and significant interpersonal implications for female patients, little research has looked for specific mediating and moderating factors, such as coping strategies that dictate how women adjust to the social implications of their disease.

Relational-Cultural Theory

Relational-cultural theory is another feminist theory that might help clarify the role of gender-related stress in disease adjustment. Relational-cultural theory suggests that growth-fostering relationships are at the core of human development, especially for women, and that a lack of growth-fostering relationships is a major predictor of psychological distress (Judith V. Jordan, 2001). This powerful drive towards connection may have negative consequences when mutuality in relationships is threatened.

According to the "central relational paradox," one attempts to preserve connection in non-mutual relationships by paradoxically keeping parts of oneself out of the relationship (Jordan, 2001; Miller & Stiver, 1997). Consonant with this theory, Jack (1991) explained that some women internalize the idea that in order to develop and maintain intimate connections, they must engage in "self-silencing" – a process of withholding emotions, opinions, strengths and capabilities perceived to be threatening to others. Although the goal of self-silencing is to maintain a sense of intimacy, harmony and connectedness with

FEMINIST PERSPECTIVE CHRONIC DISEASE

others, it actually creates disconnection and inauthenticity because parts of oneself are unknown to the other (Jack, 1991; 2011).

Research provides support for the idea that certain schemas of how to create and maintain safe, intimate relationships may cause women distress (Jack, 2011). A large body of work has established associations between silencing the self and depression (Carr & Gilroy, 1996; Jack & Dill, 1992); as self-silencing increases, so does depression, and vice versa (Cramer, Gallant, & Langlois, 2005; Jack & Dill, 1992). Self-silencing has been shown to be important in understanding mental health disorders that are more prevalent among women, such as eating disorders. Withholding oneself from relationships to maintain connection has been strongly associated with internalization of the thin-body ideal, body image dissatisfaction, and disordered eating (Geller et al., 2000; Morrison & Sheahan, 2009; Piran & Cormier, 2005). Furthermore, in samples of women with chronic disease, self-silencing has been associated with decreased self-care (cancer; Kayser, Sormanti, & Strainchamps, 1999) and adherence to treatment (HIV; Brody et al., 2014b). In sum, research suggests that the stress associated with withholding thoughts, needs and actions from others may interfere with one's ability to address one's own needs, and that this may negatively impact psychological and physical health. Research is lacking, however, on the impact of self-silencing on coping specifically with disease-related interpersonal stress.

Emotional Approach Coping

Clearly, interpersonal relationships are a crucial aspect of female development as connection and mutual relationships are key elements of women's psychological health. It is not surprising that emotional approach coping (EAC), a strategy involving

FEMINIST PERSPECTIVE CHRONIC DISEASE

interactions with others, is well documented as a successful coping strategy more effectively used by women than men (Stanton, Kirk, Cameron, & Danoff-Burg, 2000a). EAC is an approach-oriented emotion-focused coping strategy that includes emotion processing, or actively acknowledging and exploring emotions to come to an understanding, and emotion expression, or communicating one's emotional experience to others (Austenfeld & Stanton, 2004). Coping through these processes facilitates habituation to and labeling of emotions, cognitive reappraisal of stressors, clarification and pursuit of goals and strengthened social relationships (Annette L. Stanton & Low, 2012). The two levels of EAC are thought to be most effective when used in sequence, and when used in response to interpersonal, uncontrollable stressors in a socially receptive environment (Stanton et al., 2000a; Stanton et al., 2000b). Though studies could not be found that examine this specifically in the context of disease-related interpersonal stress, substantial research has documented EAC's effectiveness among women coping with chronic illnesses. Specifically, EAC has been associated with lower affective pain and depression symptoms in women coping with chronic myofascial pain (J. A. Smith, Lumley, & Longo, 2002), lower levels of distress in women suffering from failed infertility treatment (Berghuis & Stanton, 2002), and higher levels of self-reported physical health, vigor and survival in women with breast cancer (Reynolds et al., 2000; Stanton et al., 2000b).

Although women's more typical orientation towards connection may be one reason why EAC is generally so effective, this orientation may also interfere with the selection and effectiveness of this adaptive strategy. A greater focus on others and relationships, as understood by unmitigated communion and relational-cultural theory,

FEMINIST PERSPECTIVE CHRONIC DISEASE

may heighten some women's sensitivity to the impact of their health condition on their interpersonal relationships, and encourage self-neglect, self-criticism and self-silencing. The concepts of unmitigated communion and self-silencing may help to understand how gender-related stressors influence the selection and effectiveness of strategies like EAC, which depend upon a focus on the self and dependence upon others to help take care of one's needs. For example, a woman with high levels of unmitigated communion or self-silencing might be less likely to select or effectively use emotional expression as a coping strategy because of her fears about the consequences it might have for others or her relationships.

Chronic Disease of Interest: Celiac Disease

Many chronic illnesses, such as rheumatoid arthritis, fibromyalgia, breast cancer and multiple sclerosis are more common among women than men (Harbo, Gold, & Tintoré, 2013; Kvien et al., 2006; Yunus, 2002). These diseases take a significant psychological toll on women, which may be due to the considerable impact they have on interpersonal functioning and relationships. Given that interpersonal stressors affect women more significantly and that interpersonal stress may be associated with women's poorer adjustment to the psychological and social consequences of chronic disease, it is important to study an illness that: (1) disproportionately affects women; and (2) has a significant impact on social relationships, including necessary navigation of disease-related social interactions. These conditions allow us to learn more about the role of the gendered context in responding to the interpersonal consequences of chronic disease.

Celiac Disease (CD), an autoimmune disorder characterized by impairing symptoms that are triggered by the consumption of gluten, satisfies these criteria set forth

FEMINIST PERSPECTIVE CHRONIC DISEASE

above. Women represent approximately two-thirds of the CD population (Megiorni et al., 2008). They consistently report more pronounced symptoms (Midhagen & Hallert, 2003), lower quality of life (Hallert et al., 1998, 2003; Zarkadas et al., 2006) and poorer psychological well-being (Roos, Kärner, & Hallert, 2006) than do men affected by CD. Importantly, CD is a uniquely social disease: given that eating is often a social activity and that the only treatment is a strict, lifelong gluten-free diet, CD may give rise to significant interpersonal stress. Indeed, eating is embedded within processes that give meaning to everyday lives, such as caring for and being cared by others (Delormier, Frohlich, & Potvin, 2009). Eating is one way by which people interact with one another, and as a result one's feelings about eating and eating behaviors can be significantly impacted by interpersonal factors, such as peer pressure (e.g., Lieberman, Gauvin, Bukowski, & White, 2001). Not surprisingly, many studies support the idea that reduced quality of life in CD is largely the result of the interference of the disease and its associated treatment with social and leisure activities (Black & Orfila, 2011; Lorenzo et al., 2011; Zarkadas et al., 2013). Diagnosis of CD is associated with a number of interpersonal stressors, including unwanted visibility and self-disclosure, feeling neglected or forgotten and experiencing difficult emotions including isolation, shame and fear (A. Sverker, Hensing, & Hallert, 2005).

Research has begun to reveal why women with CD struggle significantly more than men. Women experience CD as having a greater disease burden associated with necessary dietary restrictions (Hallert et al., 2002), and some researchers have hypothesized that this is related to the female gender role. Sverker and colleagues (2009) suggest that for women with families, who work professionally and take care of family

FEMINIST PERSPECTIVE CHRONIC DISEASE

members in their household, CD imposes a “triple burden.” For these women, food-related CD activities take away from the little time left for oneself after paid and unpaid work is finished. Interviews, which highlight that women with CD experience significant distress due to the restrictions imposed upon socializing with friends (Lee et al., 2012), provide further support for the significance of the female gender role. Despite connection between the disease burden and gendered processes, these challenges have never been studied within a feminist framework. Furthermore, no study has attempted to understand how women cope with these difficulties, as well as what the role of interpersonal relationships might be in bolstering or hindering their ability to cope.

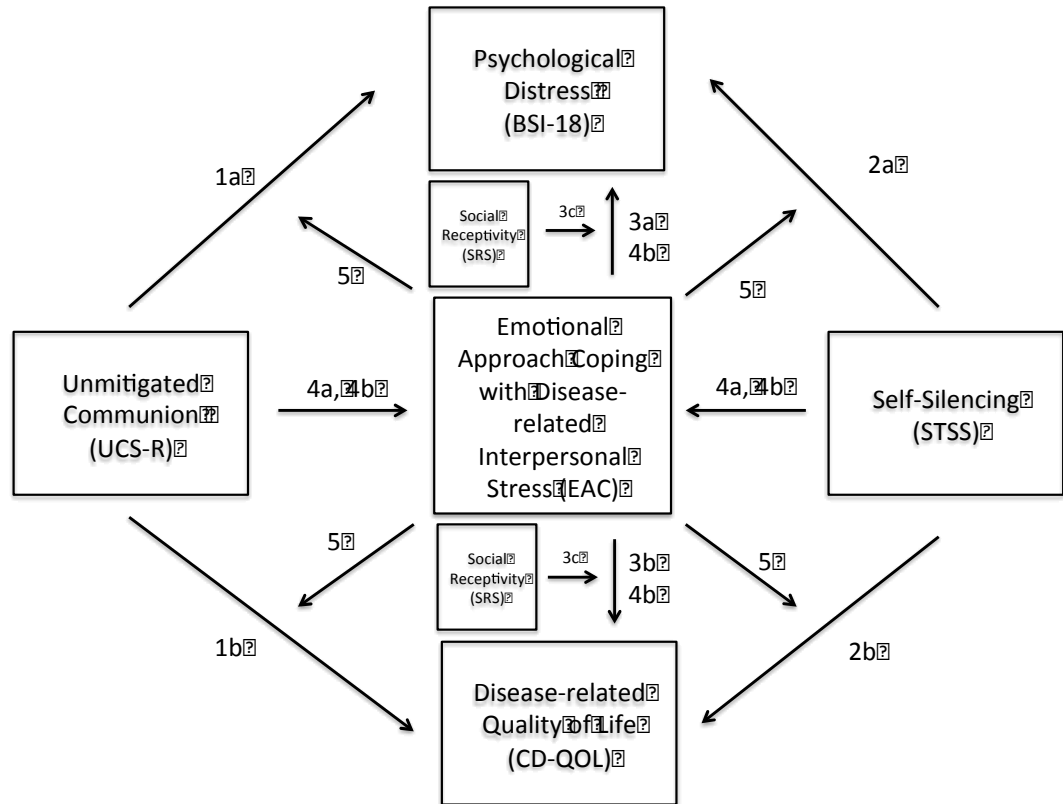
Chapter 2: Statement of the Problem

Chronic diseases carry psychological and social consequences that require significant adjustment. While the burgeoning literature on this topic has illuminated a widespread gap in outcomes between men and women, research has been lacking on the role of gender-related stress in the interpersonal implications of chronic disease. The research described above demonstrates how constructs related to gender-related stress may provide important avenues for understanding women's adjustment in the interpersonal domain of chronic disease. The purpose of the present study is to investigate how gender-related stress, including traits (i.e., unmitigated communion) and relationship schemas (i.e., self-silencing), might impact adjustment to Celiac Disease in women. Furthermore, it examines the potential role of emotional approach coping as a mediator or moderator of the relation of these traits and schemas to adjustment. Both mediation and moderation analyses were conducted because of the importance of examining whether differences in EAC explain or attenuate the relationship between gender-related stress and adjustment. For example, if EAC were found to be a mediator, the present study would highlight at least one partial explanation of how gender-related stress is related to poorer adjustment. If EAC were found to be a moderator, the present study would provide a means for differentiating and identifying which women are most negatively impacted by gender-related stress. In combination, both analyses facilitate a deeper understanding of how and for whom gendered processes are detrimental to chronic disease adjustment.

Hypotheses

Hypotheses and associated measures are displayed within a stress and coping model in Figure 1.

Figure 1



The first goal of this study was to test the relation of gender-related stress to the impact of disease on one’s overall quality of life (i.e., disease-related quality of life) and psychological distress. The gender-related trait of unmitigated communion has been linked with negative outcomes in disease adjustment among women (e.g., Brody et al., 2014a; Helgeson, 2003), and is associated with greater sensitivity to interpersonal stress (e.g., Reynolds et al., 2006). Interpersonal stress may be heightened for people coping with a chronic disease requiring navigation of complex interpersonal situations, such as

FEMINIST PERSPECTIVE CHRONIC DISEASE

CD. Thus, it was hypothesized that there would be a significant relationship between unmitigated communion and adjustment. Specifically:

Hypothesis 1a: Unmitigated communion would be positively associated with higher levels of psychological distress.

Hypothesis 1b: Unmitigated communion would be negatively associated with disease-related quality of life.

Another relevant aspect of gender-related stress is gender-related relationship schemas, known as self-silencing. In CD, women frequently face self-disclosure dilemmas when their symptoms or their treatment create awkward social situations or impede their ability to socialize as they could pre-diagnosis. Not being able to disclose when necessary might lead to decreased self-care, adherence to treatment, and mutuality in relationships, as has been shown in prior research (Brody et al., 2014b; Kasyer, Sormanti & Strainchamps, 1999). Therefore, my second set of hypotheses examining the relationship between self-silencing and adjustment was:

Hypothesis 2a: Self-silencing would be positively associated with higher levels of psychological distress.

Hypothesis 2b: Self-silencing would be negatively associated with disease-related quality of life.

The second goal of this study was to examine the role of emotional approach coping, in the context of disease-related interpersonal stress, on disease adjustment in women with CD. Women who engage in emotional processing and expression in response to uncontrollable, interpersonal stressors garner significant benefits such as better psychological health and strengthened relationships (Stanton et al., 2000b; Stanton

FEMINIST PERSPECTIVE CHRONIC DISEASE

& Low, 2012). These types of stressors are especially prevalent in CD. Importantly, Stanton and colleagues (2000) have demonstrated that perceived social receptivity is important for the beneficial effects of emotional approach coping, especially emotional expression. Thus, my third set of hypotheses examined the relationship between EAC and adjustment. Specifically:

Hypothesis 3a: Emotional approach coping would be negatively associated with psychological distress.

Hypothesis 3b: Emotional approach coping would be positively associated with disease-related quality of life.

Hypothesis 3c: There would be an interaction between emotional approach coping and social receptivity in predicting these outcomes, such that emotional approach coping would be associated with more favorable outcomes in the presence of social receptivity.

Emotional approach coping was considered as a possible mediator between gender-related stress and outcomes. Women who score high on the trait of unmitigated communion are known to judge themselves based on others' evaluations of them, which may make them self-conscious about expressing difficult feelings (e.g., Fritz & Helgeson, 1998). Similarly, women who engage in self-silencing actively hide parts of themselves in order to maintain relationships (Jack, 1991). Thus, these gender-related stressors may impede upon women with CD's ability to express their emotions and their needs when their disease has created difficult and complex interpersonal situations, and this, in turn, may be detrimental to their psychological well-being and disease-related quality of life. Thus, my fourth set of hypotheses was:

FEMINIST PERSPECTIVE CHRONIC DISEASE

Hypothesis 4a: Gender-related stress would be negatively associated with emotional approach coping.

Hypothesis 4b: This relationship between gender-related stress and emotional approach coping would partially mediate negative associations between gender-related stress and outcomes.

On the other hand, emotional approach coping was considered to also protect women from gender-related stress. Because emotional approach coping is associated with better psychological health and strengthened relationships (e.g., (Stanton et al., 2000a; Stanton & Low, 2012), this coping process may serve to buffer women from gender and disease-related stressors. Therefore, my final hypothesis was:

Hypothesis 5: Emotional approach coping would moderate the relationship between gender-related stress and outcomes, such that the negative impact of gender-related stress may be attenuated, or buffered by use of emotional approach coping.

Chapter 3: Methods

Design

The current study was designed as a correlational field study. The study used an online survey method with open-ended questions and select measures. The focus was on investigating three potential predictors of psychological adjustment (psychological distress and disease-related quality of life): unmitigated communion, self-silencing, and emotional approach coping. In addition to investigating main effects of these variables on adjustment, emotional approach coping was examined as a possible mediator or moderator of the relationships among gender-related stress variables (unmitigated communion and self-silencing) and adjustment.

Participants

A power analysis was conducted for each of the planned tests in order to determine the number of participants needed for the study. The sample size was largest for the mediation analysis; according to Fritz and MacKinnon's (2007) recommendations, at least 148 participants would be needed to achieve a power of .80 to detect mediation with small to medium effect sizes using non-parametric bootstrapping at a significance level of .05. The effect sizes were based on previous estimates of the strength of the relationships between the predictors and outcomes of interest demonstrated in the literature (e.g., Ali, Oatley, & Toner, 2002; Danoff-Burg, 2004; Frank & Thomas, 2003; Nagurney, 2008; Smith et al., 2002; Stanton et al., 2000b).

Female participants needed to meet the following eligibility criteria: at least 18 years of age, diagnosed with Celiac Disease by a healthcare provider and attempting to follow a gluten-free diet most or all of time. The latter criteria was included in order to

FEMINIST PERSPECTIVE CHRONIC DISEASE

emphasize the unique stressors associated with navigating the diet, such as the daily challenge of securing food that is safe to eat while engaging in desirable, yet conflicting activities (e.g., going out to eat with friends). Furthermore, prior research of individuals with Celiac Disease demonstrates that adherence to the diet is: 1) a significant aspect of disease-related adjustment; and 2) critically associated with disease-related outcomes (e.g., Hallert et al., 2003; Mustalahti et al., 2002). Overall, 406 women gave informed consent and enrolled in the study. One hundred and sixty-eight participants dropped out at some point during the survey, with only 244 completing every measure. Two hundred and ninety-four participants completed at least one gender-related stress measure, while 268 participants completed the coping measure and 344 participants completed at least one outcome measure.

In order to use all information available to evaluate hypotheses, missing data was managed using full information maximum likelihood (FIML) in Mplus. FIML uses each case's available data to compute maximum likelihood estimates of parameters that are missing. Thus, participants who completed any portion of the survey may be included in analyses. Among these participants, the average age was 42.71 years (SD = 15.48; range = 18-84). The large majority of participants was from the U.S. (96.4%) and identified as white (93.2%). Most identified as heterosexual (94.0%) and were married or in a committed relationship (74.2%). The majority was employed full-time (48.3%), part-time (14.6%) or as a student (10.1%), with an education level including 2 or more years of college (84.3%) and an annual household income of \$60,000 or more (68.1%). A small number (14.8%) reported living with a family member or roommate who also had been diagnosed with Celiac Disease.

FEMINIST PERSPECTIVE CHRONIC DISEASE

The vast majority of participants were diagnosed with Celiac Disease by a gastroenterologist (71.8%) or primary care physician (20.3%) using a blood serum test (82.5%), intestinal biopsy (81.0%), genetic test (13.7%) and/or presenting symptoms (21.6%). The average age of diagnosis was 36.07 years of age (SD = 13.86, range = 0-68) and average time passed since diagnosis at the time of completing the survey was 92.30 months (SD = 110.92, range = 0-840). Many participants reported being diagnosed with at least one other autoimmune disease (45.5%) and/or mental health condition (21.8%). For a more comprehensive picture of participants' demographic information, see Table 1.

Table 1

<i>Demographics</i>		
<i>Race/Ethnicity</i>	<i>N</i>	<i>Percentage</i>
African American/Black	1	.3%
Asian American/Pacific Islander	1	.3%
Asian Indian/Pakistani	2	.6%
Middle-Eastern/Arab	1	.3%
Biracial/Multiracial	4	1.2%
Hispanic/Latino(a)	4	1.2%
Native American/Native Alaskan	3	.9%
White	248	72.1%
Other	2	.6%
Unknown	78	22.7%
<i>Sexual Orientation</i>		
<i>Sexual Orientation</i>	<i>N</i>	<i>Percentage</i>
Heterosexual or Straight	251	73.0%
Gay or Lesbian	5	1.5%
Bisexual	7	2.0%
Other	4	1.2%
Unknown	77	22.4%
<i>Relationship Status</i>		
<i>Relationship Status</i>	<i>N</i>	<i>Percentage</i>
Married or Married-like Relationship	171	49.7%
Committed Relationship	27	7.8%
Divorced	16	4.7%
Single	46	13.4%
Separated	3	.9%
Widowed	4	1.2%
Unknown	77	22.4%

FEMINIST PERSPECTIVE CHRONIC DISEASE

<i>Employment Status</i>	<i>N</i>	<i>Percentage</i>
Full-time	133	38.7%
Part-time	39	11.3%
Student	27	7.8%
Unemployed	44	12.8%
Retired	24	7.0%
Unknown	77	22.4%

<i>Education Level</i>	<i>N</i>	<i>Percentage</i>
Grade school	4	1.2%
High school	38	11.0%
Some college/associate's degree	52	15.2%
College	94	27.3%
Graduate school	79	23.0%
Unknown	77	22.4%

<i>Household Income</i>	<i>N</i>	<i>Percentage</i>
Less than \$30,000	33	9.6%
\$30,000 - 59,999	49	14.2%
\$60,000 - 99,999	68	19.8%
\$100,000 - 149,999	60	17.4%
\$150,000+	47	13.7%
Unknown	87	25.3%

<i>Diagnosing Practitioner</i>	<i>N</i>	<i>Percentage</i>
Primary care provider (M.D.)	64	18.6%
Primary care provider (N.P. or P.A.)	6	1.7%
Specialist (Gastroenterologist)	247	71.8%
Other	27	7.8%

<i>Method of Diagnosis</i>	<i>N</i>	<i>Percentage</i>
Blood serum test	283	82.5%
Intestinal biopsy	278	81.0%
Genetic test	47	13.7%
Symptoms on/off gluten free diet	74	21.6%
Other	16	5.3%

*Percentages exceed 100% since participants could list multiple methods of diagnosis

<i>Autoimmune Disease</i>	<i>N</i>	<i>Percentage</i>
Addison's disease	2	.6%
Thyroid disease	90	26.2%
Rheumatoid arthritis	11	3.2%
Crohn's disease	3	.9%
Ulcerative colitis	6	1.7%

FEMINIST PERSPECTIVE CHRONIC DISEASE

Dermatitis herpetiformis	33	9.6%
Diabetes (Type I)	8	2.3%
Multiple sclerosis	1	.3%
Sjogren's syndrome	11	3.2%
Other	67	19.5%

* Participants could list multiple diagnoses

<i>Severity of Symptoms</i>	<i>N</i>	<i>Percentage</i>
Very mild	24	7.0%
Mild	14	4.1%
Moderate	73	21.2%
Severe	136	39.5%
Very severe	97	28.2%

<i>Frequency of Symptoms</i>	<i>N</i>	<i>Percentage</i>
Never	38	11.0%
Rarely	101	29.4%
Sometimes	73	21.2%
Often	75	21.8%
Always	57	16.6%

<i>Disease Factors</i>	<i>M</i>	<i>SD</i>
Age at diagnosis (years)	36.07	13.86
Time since diagnosis in months (years)	92.29 (7.69)	110.92 (9.24)

Procedure

Participants were recruited through advertisements in local specialty clinics, postings on online support websites, advertisements on popular social media sites, advertisements through the University of Maryland FYI listserv, flyers posted in local grocery stores and restaurants with gluten free offerings, and through snowball sampling.

The survey was administered online through the Qualtrics system. Participants were provided with a link to the survey. Once participants clicked on the link to access the survey, they immediately viewed an informed consent page and endorsed that they are female, at least 18 years of age, have a diagnosis of Celiac Disease made by a healthcare provider, are following a gluten-free diet, and agree with the parameters of the

FEMINIST PERSPECTIVE CHRONIC DISEASE

survey. The survey began with an open-ended question about interpersonal stress involving Celiac Disease. Specifically, participants were asked to describe the most stressful interpersonal aspect of living with Celiac Disease in the past month, and to describe how they have coped with this stress. They were also asked to make Likert-type ratings about the frequency, duration and severity of the stressor, as well as how much their coping efforts have been helpful in managing it. Following these questions, participants completed the Emotional Approach Coping Scale to indicate their use of this strategy in this context, including 3-items about perceived social receptivity. After that, participants completed scales pertinent to gender-related stress (Silencing the Self Scale, Revised-Unmitigated Communion Scale), psychological distress (Brief Symptom Inventory-18), disease-related quality of life (Celiac Disease-Quality of Life Scale), and demographics. Finally, participants were provided with a brief explanation of the rationale of the study. The total survey took participants 20-30 minutes.

Measures

Demographics. Information regarding age, race/ethnicity, method of diagnosis (serology or biopsy), time since diagnosis, additional medical diagnoses, and socioeconomic variables were included on the demographic form (see Appendix C). In addition, the form included questions about Celiac Disease specific problems, including an open-ended question about experienced disease symptoms and Likert-type ratings about their frequency, duration and severity.

Unmitigated communion. Helgeson (1993) constructed an 8-item, Likert-type scale to measure the extent to which patients place others' needs before their own and experience distress over concern for others. The Unmitigated Communion Scale has since

FEMINIST PERSPECTIVE CHRONIC DISEASE

been revised (H. L. Fritz & Helgeson, 1998; see Appendix H) to generalize to a wide array of populations, and now includes 9-items. Sample items include “I always place the needs of others above my own,” “I can’t say ‘No’ when someone asks me for help” and “I often worry about other people’s problems.” Respondents indicate the extent to which they agree or disagree with each item on a 5-point scale, with higher scores indicating greater agreement. Scores are calculated by summing all 9-items (ranging from 9 to 45), with higher total scores indicating greater levels of unmitigated communion. Previous research has shown that scores on this scale demonstrates acceptable internal consistency (range = .70 to .80) and high test-retest reliability (Fritz & Helgeson, 1998; Helgeson, 1994; Helgeson & Fritz, 1996; 1999). In the present study, internal consistency was acceptable ($\alpha = .73$) and similar to other studies. Higher scores on the Unmitigated Communion Revised Scale have been shown to be associated with anxiety and depression in women suffering from chronic illnesses such as rheumatoid arthritis, breast cancer and HIV (Brody et al., 2014a; Helgeson, 2003; Trudeau et al., 2003).

Silencing the self. Jack and Dill (1992; see Appendix G) developed the Silencing the Self Scale (STSS) as a 31-item Likert-type measure to assess the construct of self-silencing in relationships. Sample items include “I try to bury my feelings when I think they will cause trouble in my close relationship(s)” and “Instead of risking confrontations in close relationships, I would rather not rock the boat.” Response items range from 1 (“strongly disagree”) to 5 (“strongly agree”). After reverse-scoring five items, scores are determined by summing all 31 items for a full-scale score (ranging from 31 to 155), with higher total scores indicate greater levels of self-silencing, or less voice in relationships. The STSS includes four subscales: (1) Externalized Self-Perception, or judging the self

FEMINIST PERSPECTIVE CHRONIC DISEASE

by external standards; (2) Care as Self-Sacrifice, or securing attachments by putting the needs of others before the self; (3) Silencing the Self, or inhibiting one's self-expression and action to avoid conflict and possible loss of relationship; and (4) The Divided Self, or the experience of presenting an outer compliant self to live up to feminine role imperatives while the inner self grows angry and hostile (Jack & Dill, 1992). The STSS total score has demonstrated good internal consistency (range = .87 to .92) with diverse samples of women, including cancer and HIV patients (Besser et al., 2003; Sormanti et al., 1997; Shouse & Nilsson, 2011). Alphas on subscales are also satisfactory (range = .74 to .94), except for Care as Self-Sacrifice (range = .60 to .81), which should be used separately with caution (Jack & Dill, 1992). Both the full scale and its subscales have demonstrated strong, positive relationships with elevated depression, decreased self-care, and low social support (Besser, Flett, & Davis, 2003; Jack & Dill, 1992). In the present study, only the total score has been analyzed in order to gain a more comprehensive and robust measure of self-silencing. In the present study, internal consistency for the total scale was excellent ($\alpha = .90$).

Emotional approach coping. Stanton, Kirk, Cameron and Danoff-Burg (2000a; see Appendix E) constructed an 8-item scale to measure self-reported emotional approach coping. The Emotional Approach Coping Scale (EAC) consists of two 4-item subscales for Emotional Processing and Emotional Expression. The Emotional Processing subscale assesses people's attempts to understand, explore and acknowledge their emotions, such as "I take time to figure out what I'm really feeling" and "I acknowledge my emotions." The Emotional Expression subscale assesses the volitional expression of one's emotions, such as "I take time to express my emotions" and "I feel free to express my emotions."

FEMINIST PERSPECTIVE CHRONIC DISEASE

Response options for items range from 1 (“I don’t do this at all”) to 4 (“I do this a lot”), and items are averaged to yield a mean EAC score (ranging from 1 to 4) as well as two subscale scores (ranging from 1 to 4). Higher scores indicate greater EAC. In both dispositional and situational versions, the EAC subscales demonstrate high internal consistency (range = .72 to .94) and test-retest reliability (range = .72 to .78; Austenfeld & Stanton, 2004). In the study of chronic disease, total EAC has been shown to be associated with greater psychological adjustment in individuals with chronic pain and breast cancer, and couples with infertility (Berghuis & Stanton, 2002; Smith et al., 2002; Stanton et al., 2000b). Following work by Batenburg and Das (2014), the overall score of the situational scale was used to test hypotheses. Emotional processing and expression subscales were analyzed in exploratory and post hoc analyses. Internal consistency was excellent for each subscale (processing $\alpha = .87$, expression $\alpha = .94$) and for the situational scale overall ($\alpha = .92$).

Social receptivity. Stanton and colleagues (2000b; see Appendix F) designed a three-item, Likert-type scale to assess perceived receptivity of the social network to women’s cancer-related expression. Three items (i.e., “I have people to talk to about my worries concerning cancer,” “I feel free to express all my feelings about cancer to those close to me,” “There are people I can count on whenever I want to talk about my experience with cancer”) were rated on 5-point scales ranging from 1 (“strongly disagree”) to 5 (“strongly agree”) and averaged for a total score. In the present study, the scale will be modified such that “cancer” will be replaced with “Celiac Disease.” In research with women with breast cancer, the items have been shown to have high internal consistency (range = .75 to .84) and acceptable test–retest reliability (.59; Stanton et al.,

2000b). In women with breast cancer, social receptivity has been shown to moderate the relationship between emotional expression and quality of life; higher levels of emotional expression are related to enhanced quality of life in those who rate their social contexts as highly receptive (Stanton et al., 2000b). In the present study, internal consistency was good ($\alpha = .84$).

Psychological distress. The Brief Symptom Inventory is an 18-item questionnaire commonly used to quantify overall psychological distress (Derogatis, 2000; see Appendix I). Patients rate their level of distress during the past week on 18 symptoms using a 5-point Likert-type scale ranging from 0 (“not at all”) to 4 (“extremely”). The scale assesses three symptom dimensions, with 6 items each: (1) Somatization; (2) Depression; and (3) Anxiety. Scores for each subscale are calculated by summing individual items. A Global Severity Index (GSI) is calculated by summing all 18 items. Higher scores indicate greater distress and a score higher than 59 indicates significant psychological distress. The BSI-18 has been shown to have good internal consistency in a variety of samples (in community samples, range = .74 to .89 across subscales and GSI; Derogatis, 2000) including individuals with gastrointestinal disorders (e.g., Dorn et al., 2010a). When compared to the 90-item measure from which the BSI-18 was derived (Symptoms Checklist-90; Derogatis, Rickels, & Rock, 1976), correlations between the three symptom dimensions on each scale are high (range = .91 to .96), indicating that little information is lost with a reduced number of items. In the present study, only the GSI is used. In the present study, internal consistency for the total scale was excellent ($\alpha = .94$).

FEMINIST PERSPECTIVE CHRONIC DISEASE

Disease-related quality of life. Dorn and colleagues (2010b; see Appendix J) constructed a 20-item scale to measure Celiac Disease quality of life. Sample items include “I feel limited by this disease,” “I feel like I think about food all the time,” and “I have trouble socializing because of my disease.” Response items indicate the extent to which items describe participants’ feelings as they reflect over the past month of their lives, on a 5-point, Likert-type scale ranging from 1 (“not at all”) to 5 (“a great deal”). Scores are calculated by summing the reverse score of all 20 items (ranging from 20 to 100), with higher total scores indicating a better quality of life and less impact of illness on daily life. An exploratory factor analysis of The Celiac Disease-Quality of Life Scale (CD-QOL Scale) performed by Dorn and colleagues (2009) revealed four clinically relevant subscales: (1) Limitations; (2) Dysphoria; (3) Health Concerns; and (4) Inadequate treatment. The CD-QOL scale has demonstrated good internal consistency (exceeding .70; Dorn et al., 2010b). Both the full scale and its subscales are associated with less daily impairment, psychological distress and abdominal pain (Dorn et al., 2010b). In the present study, only the total score has been analyzed. The internal consistency was excellent ($\alpha = .92$).

Chapter 4: Results

The results chapter includes attrition data, preliminary analyses, analysis of the research questions and post hoc exploratory analyses.

Attrition

The total number of participants who completed each measure can be seen in Table 2. Though 406 participants gave informed consent, 62 dropped out after providing disease-related demographic information and prior to completing the first outcome measure (CD-QOL). Ten more dropped out prior to completing the next outcome measure (BSI-18) and 15 more stopped prior to completing the first assessment of gender-related stress (UCS-R). The greatest drop out point occurred when filling out the Silencing the Self Scale (35 participants), which came next. Following qualitative responses about the most stressful interpersonal aspect of living with CD, 26 additional participants dropped out before completing the Emotional Approach Coping Scale. Finally, a significant number of participants did not complete general demographic measures, which were given at the end of the survey (e.g., 77 were missing for race/ethnicity, 87 were missing for household income).

Preliminary Analyses

Analyses were completed using the statistical package software IBS SPSS Version 20 and statistical package software Mplus 7.4. Because Mplus uses a robust estimator, no assumptions about normality of distribution of variables were made. In the case of individually missing items, scale scores were calculated by averaging the person's responses to completed items, following recommendations by Schafer and Graham (2002). In the case of entirely incomplete measures, Full Information Maximum

FEMINIST PERSPECTIVE CHRONIC DISEASE

Likelihood (FIML) was used to make estimates consistent with raw data and maximize power.

Each variable was checked in SPSS for internal consistency and univariate outliers. All of the scales yielded acceptable internal consistency as indicated by Cronbach's alphas ranging from .73 to .93. Each variable was assessed for outliers by converting raw scores to standardized scores (i.e., z-scores) and assessing for data points that deviated from the mean of all cases. Values that were three or more standard deviations away from the mean were considered outliers. The number of outliers per scale ranged from 5 to 7. There were no participants who had outlier scores on more than one scale. Because all values appeared to be valid responses from members of the sample, all data points were retained for analyses. Reliability estimates, range, means, and standard deviations of all of the scales are presented in Table 2.

Table 2

Reliability estimates, range, means, and standard deviations for variables

<i>Measure</i>	<i>N</i>	<i>Possible Range</i>	<i>Scoring</i>	<i>Alpha</i>	<i>Sample Range</i>	<i>Mean</i>	<i>SD</i>
UCS-R	329	9-45	Scale 1-5 (higher=more unmitigated communion)	.73	9 – 43	30.36	5.85
STSS	294	31-155	Scale 1-5 (higher=more self-silencing)	.90	38 – 136	80.19	21.82
EAC	268	1-4	Scale 1-4 (higher=greater emotional approach coping)	.92	1 – 4	2.62	.77
EAC-P	268	1-4	Scale 1-4 (higher=greater emotional processing)	.87	1 – 4	2.68	.82
EAC-E	268	1-4	Scale 1-4 (higher=greater emotional expression)	.94	1 – 4	2.55	.88
SRS	344	1-5	Scale 1-5 (higher=greater social receptivity)	.84	1 – 5	3.71	.96
BSI-18	334	0-72	Scale 0-4 (higher=higher psychological distress)	.94	0 – 67	13.34	13.37
CD-QOL	344	20-100	Score 1-5 (higher=better quality of life)	.92	24 – 96	61.31	16.34

Note. UCS-R=Unmitigated Communion Scale-Revised; STSS=Silencing the Self Scale; EAC=Emotional Approach Coping Scale; EAC-P=Emotional Processing; EAC-E=Emotional Expression; SRS=Social Receptivity Scale; BSI=Brief Symptom Inventory; CD-QOL=Celiac Disease Quality of Life Scale

FEMINIST PERSPECTIVE CHRONIC DISEASE

Looking more closely at the gender-related stress variables in Table 2, one can see that the mean scores on unmitigated communion ($M = 30.36$, $SD = 5.85$) are comparable to other clinical and community samples, such as one of women with rheumatoid arthritis ($M = 31.35$, $SD = 6.11$; Danoff-Burg et al., 2004) and one of healthy women ($M = 29.97$, $SD = 5.24$; Danoff-Burg, Mosher, & Grant, 2006). Mean scores on self-silencing ($M = 80.19$, $SD = 21.82$) are slightly higher than other clinical and community samples, such as one of women with irritable bowel syndrome ($M = 77.2$, $SD = 20.5$; Ali et al., 2002) and one of healthy women ($M = 77.1$, $SD = 16.2$; (Cramer & Thoms, 2003).

Mean scores on emotional approach coping (processing: $M = 2.68$, $SD = .82$; expression $M = 2.55$, $SD = .88$) are slightly lower than those of clinical and community samples, such as one of women with breast cancer (processing: $M = 3.00$, $SD = .72$; expression $M = 2.95$, $SD = .84$; Stanton et al., 2000b) and one of healthy women (processing: $M = 3.85$, $SD = .63$; expression $M = 2.79$, $SD = .73$; Stanton et al., 2000a). Finally, mean scores on social receptivity ($M = 3.71$, $SD = .96$) were slightly lower than expected from Stanton et al.'s development of the scale in women with breast cancer ($M = 4.15$, $SD = .98$; Stanton et al., 2000b).

Looking more closely at the outcome variables in Table 2, one can see that the mean scores of psychological distress (BSI-18; $M = 13.34$, $SD = 13.37$) are in the average range (57th percentile) as compared to female community and oncology norms (Derogatis, 2000). Finally, mean scores on disease-related quality of life (CD-QOL; $M = 61.31$, $SD = 16.34$) fall in the range of what one might expect for a community sample of women with Celiac Disease with varying amount of time passed since diagnosis. In the development of the scale, researchers found mean CD-QOL scores ranging from $M =$

FEMINIST PERSPECTIVE CHRONIC DISEASE

51.43 (Dorn et al., 2009) to $M = 81.03$ (Zingone et al., 2013) in predominantly female samples.

Demographic variables. A correlation matrix of Pearson's r correlation coefficients was created to capture information about the relationships among demographic variables and outcome variables; significant relationships were determined by performing t -tests at the .05 level (see Table 3). This matrix demonstrates that older age, more education, more income and more time since diagnosis significantly correlated with lower levels of psychological distress, while more severe and more frequent symptoms significantly correlated with greater levels of psychological distress. Older age, more education, more income and more time since diagnosis significantly correlated with better disease-related quality of life, while more severe and more frequent symptoms significantly correlated with poorer disease-related quality of life. Effect sizes of correlations between demographic variables and outcome variables ranged from small to moderate.

FEMINIST PERSPECTIVE CHRONIC DISEASE

Table 3

Correlations among demographic and outcome variables

Variable	<i>M</i>	<i>SD</i>	1	2	3	4	5	6	7	8	9
1. Age (years)	42.71	15.48	-								
2. Education	<i>See Table 1</i>		.18**	-							
3. Income	<i>See Table 1</i>		.15*	.34**	-						
4. Time since diagnosis (years)	7.73	1.31	.40**	.14*	.01	-					
5. Autoimmune disease	.57	.84	.22**	-.06	-.06	.03	-				
6. Symptom severity	3.77	1.12	-.08	-.16*	-.16**	-.06	.07	-			
7. Symptom frequency	3.04	1.27	.22	-.26**	-.13*	-.22**	.22**	.36**	-		
8. BSI-18	13.34	13.37	-.25**	-.31**	-.34**	-.17**	.08	.29**	.37**	-	
9. CD-QOL	61.31	16.34	.25**	.24**	.16*	.38**	-.08	-.23**	-.34**	-.58**	-

Note. $N=344$. Autoimmune disease=total number of autoimmune disease diagnoses, range 0-5; Symptom severity and frequency range 1-5; BSI=Brief Symptom Inventory, range 0-72; CD-QOL=Celiac Disease Quality of Life Scale, range 20-100

* $p < .05$

** $p < .01$

Analysis of Research Questions

Correlations. Pearson correlations were calculated to determine the relationships among individual criterion variables (unmitigated communion, self-silencing, emotional approach coping) and between the criterion variables and outcome variables (psychological distress, disease-related quality of life); significant relationships were determined by performing *t*-tests at the .05 level. Following hypotheses 1-3 and 4a, we expected significant *t*-tests for: positive associations between: (a) gender-related stress variables and psychological distress; (b) emotional approach coping and disease-related quality of life; and negative associations between: (a) gender-related stress variables and disease-related quality of life; (b) emotional approach coping and psychological distress.

FEMINIST PERSPECTIVE CHRONIC DISEASE

A correlation matrix of Pearson's r correlation coefficients was created to capture information about the relationships among all variables (see Table 4). All of the correlations were in the expected direction, confirming hypotheses.

Hypothesis 1. More specifically, following hypotheses 1a and b, unmitigated communion correlated with increased psychological distress ($r = .41, p < .01$) and decreased disease-related quality of life ($r = -.32, p < .01$). Effect sizes were moderate. In other words, participants who had a tendency to prioritize others needs before their own had more difficulty adjusting to the interpersonal stress associated with CD.

Hypothesis 2. Following hypotheses 2a and b, self-silencing correlated with increased psychological distress ($r = .52, p < .01$) and with decreased disease-related quality of life ($r = -.30, p < .01$). Effect sizes were moderate (quality of life) and large (distress). Put differently, participants who were more likely to silence their emotions and opinions in order to maintain connection and harmony in relationships had more difficulty adjusting to the interpersonal stress associated with CD.

Hypothesis 3. Following hypotheses 3a and 3b, emotional approach coping had correlations with decreased psychological distress ($r = -.20, p < .01$) and increased disease-related quality of life ($r = .15, p < .05$). Effect sizes were small. That is to say, participants who processed and expressed their feelings in interpersonally stressful situations demonstrated better psychological adjustment to CD.

Hypothesis 4. Following hypothesis 4a, emotional approach coping was correlated with unmitigated communion ($r = -.26, p < .01$) and with self-silencing ($r = -.50, p < .01$). Effect sizes were moderate to large. Thus, participants who were more likely to prioritize others needs before their own and silence their emotions and opinions

FEMINIST PERSPECTIVE CHRONIC DISEASE

were less likely to cope in interpersonally difficult situations by processing and expressing their feelings.

Table 4

Correlations among individual criterion and outcome variables

	<i>M</i>	<i>SD</i>	1	2	3	4	5
1. UCS-R	30.36	5.85	-				
2. STSS	80.19	21.82	.56**	-			
3. EAC	2.62	.77	-.26**	-.50**	-		
4. BSI-18	13.34	13.37	.41**	.52**	-.20**	-	
5. CD-QOL	61.31	16.34	-.32**	-.30**	.15**	-.58**	-

Note. $N=344$. UCS-R=Unmitigated Communion Scale-Revised, range 9-43; STSS=Silencing the Self Scale, range 38-136; EAC=Emotional Approach Coping Scale, range 1-4; SRS=Social Receptivity Scale, range 1-5; BSI=Brief Symptom Inventory, range 0-67; CD-QOL=Celiac Disease Quality of Life Scale, range 24-96

** $p<.01$

Exploratory Correlation Analyses. Following the same procedure, exploratory analyses were performed to assess relationships between individual subscales of the STSS and EAC scales and outcome measures (see Tables 5 and 6), as well as between individual criterion variables and subscales of the CD-QOL (see Table 7). Results in Table 5 demonstrate that each subscale of the STSS, measuring externalized self-perception, care as self-sacrifice, silencing the self and the divided self, significantly correlated with increased psychological distress and decreased disease-related quality of life and that many of these effect sizes were either moderate or large.

FEMINIST PERSPECTIVE CHRONIC DISEASE

Table 5

Exploratory correlations between STSS subscales and outcomes

	<i>M</i>	<i>SD</i>	1	2	3	4	5	6
1. Externalized self-perception	17.29	5.90	-					
2. Care as self-sacrifice	24.87	5.96	.58**	-				
3. Silencing the self	22.33	7.76	.55**	.50**	-			
4. Divided self	15.70	6.94	.60**	.39**	.74**	-		
5. BSI-18	13.34	13.37	.49**	.36**	.36**	.51**	-	
6. CD-QOL	61.31	16.34	-.36**	-.25**	-.14**	-.23**	-.58**	-

Note. *N*=344. Externalized self-perception range 6-30; Care as self-sacrifice range 11-41; Silencing the self range 9-43; Divided self range 7-34. STSS=Silencing the Self Scale; BSI=Brief Symptom Inventory, range 0-67; CD-QOL=Celiac Disease Quality of Life Scale, range 24-96
 ***p*<.01

Results in Table 6 demonstrate that the emotional expression subscale of EAC had negative correlations with unmitigated communion ($r = -.27, p < .01$) and silencing the self ($r = -.51, p < .01$). Effect sizes were moderate (unmitigated communion) and large (silencing the self). Coping through emotional expression also had a negative correlation with psychological distress ($r = -.25, p < .01$) and a positive correlation with disease-related quality of life ($r = .21, p < .01$). Effect sizes were small. The emotional processing subscale was not correlated with either outcome, but was negatively correlated with unmitigated communion ($r = -.20, p < .01$) and self-silencing ($r = -.38, p < .01$). The effect sizes were small and moderate. The two subscales were significantly correlated with one another ($r = .61, p < .01$), and the effect size was large.

FEMINIST PERSPECTIVE CHRONIC DISEASE

Table 6

Exploratory correlations between EAC subscales and outcomes

	<i>M</i>	<i>SD</i>	1	2	3	4	5	6
1. EAC - Process	2.68	.82	-					
2. EAC - Express	2.55	.88	.61**	-				
3. UCS-R	30.36	5.85	-.20**	-.27**	-			
4. STSS	80.19	21.82	-.38**	-.51*	.55**	-		
5. BSI-18	13.34	13.37	-.11	-.25**	.41**	.51**	-	
6. CD-QOL	61.31	16.34	.07	.18**	-.32**	-.29**	-.58**	-

Note. N=344. EAC – Process range 1-4; EAC – Express range 1-4; UCS-R=Unmitigated Communion Scale-Revised; STSS=Silencing the Self Scale; EAC=Emotional Approach Coping Scale; BSI=Brief Symptom Inventory; CD-QOL=Celiac Disease Quality of Life Scale
**p<.01

Results in Table 7 demonstrate significant relationships, with small to moderate effect sizes, between unmitigated communion, silencing the self, emotional approach coping and all subscales of disease-related quality of life, with the exception of the beliefs about inadequate treatment subscale. Emotional approach coping was not significantly correlated with the disease-related health concerns subscale.

FEMINIST PERSPECTIVE CHRONIC DISEASE

Table 7

Exploratory correlations using CD-QOL subscales

	<i>M</i>	<i>SD</i>	1	2	3	4	5	6	7
1. UCS-R	30.36	5.85	-						
2. STSS	80.19	21.82	.55**	-					
3. EAC	2.62	.77	-.26**	-.49**	-				
4. CD-QOL: Limitations	26.14	8.81	-.26**	-.24**	.15*	-			
5. CD-QOL: Dysphoria	15.59	4.06	-.31**	-.35**	.18**	.67**	-		
6. CD-QOL: Health concerns	14.30	5.33	-.31**	-.21**	.05	.63**	.71**	-	
7. CD-QOL: Inadequate treatment	5.38	1.49	-.00	-.03	.01	.13*	.09	.05	-

Note. N=344. UCS-R=Unmitigated Communion Scale-Revised, range 9-43; STSS=Silencing the Self Scale, range 38-136; EAC=Emotional Approach Coping Scale, range 1-4; BSI=Brief Symptom Inventory, range 0-62; CD-QOL=Celiac Disease Quality of Life Scale; Limitations range 9-45; Dysphoria range 4-20; Health Concerns range 5-25; Inadequate Treatment range 2-10

*p<.05

**p<.01

Mediation. Mediation analyses were performed using Mplus 7.4. Prior to testing these hypotheses, linear regression was used to determine demographic variables as possible covariates. Income and time since diagnosis were identified as variables explaining significant variance in psychological distress; age, time since diagnosis, severity of symptoms and frequency of symptoms were identified as explaining significant variance in disease-related quality of life. Multicollinearity among these variables was not observed. Results did not differ with and without covariates in any of the following models, so results without covariates are displayed below for simplicity.

Hypothesis 4b. Emotional approach coping was tested as a mediator of the effects of gender-related stress (unmitigated communion and self-silencing) on adjustment (psychological distress and disease-related quality of life). Results in Table 8 demonstrate

FEMINIST PERSPECTIVE CHRONIC DISEASE

that emotional approach coping does not appear to mediate the effects of unmitigated communion or silencing the self on either psychological distress or disease-related quality of life. Put simply, decreases in processing and expressing one's emotions do not explain the negative effect of gender-related stress (i.e., prioritizing others' needs and silencing one's thoughts and opinions in order to maintain connection) on psychological adjustment to CD.

Table 8

Test of EAC as mediator of the effects of gender-related stress on psychological adjustment

<i>STSS → EAC → BSI-18</i>	<i>B</i>	<i>SE</i>	<i>Z</i>	<i>p</i>
Direct effect	.34	.04	8.20	.00
Indirect effect	-.02	.02	-1.00	.32
<hr/>				
<i>STSS → EAC → CD-QOL</i>				
Direct effect	-.22	.05	-4.50	.00
Indirect effect	.00	.03	-.03	.98
<hr/>				
<i>UCS → EAC → BSI-18</i>				
Direct effect	.89	.13	6.90	.00
Indirect effect	.06	.04	1.35	.18
<hr/>				
<i>UCS → EAC → CD-QOL</i>				
Direct effect	-.84	.15	-5.78	.00
Indirect effect	-.04	.05	-.92	.36

Note. $N=344$. UCS-R=Unmitigated Communion Scale-Revised; STSS=Silencing the Self Scale; EAC=Emotional Approach Coping Scale; BSI=Brief Symptom Inventory; CD-QOL=Celiac Disease Quality of Life Scale

Due to the lack of temporal relationship between variables, mediation analyses were also performed in the reverse direction. Results in Table 9 demonstrate that emotional approach coping partially mediates the effect of psychological distress on silencing the self ($B = .13, p < .01$) and unmitigated communion ($B = .17, p < .05$); and of disease-related quality of life on silencing the self ($B = -.09, p < .05$) and unmitigated communion ($B = -.01, p = .05$). Effect sizes are moderate, except for the indirect effect of

FEMINIST PERSPECTIVE CHRONIC DISEASE

disease-related quality of life on unmitigated communion, which is small. Put simply, decreases in emotional processing and expression explain the negative effect of psychological adjustment on gender-related stress (i.e., prioritizing others' needs and silencing one's thoughts and opinions in order to maintain connection).

Table 9

Test of EAC as mediator of the effects of psychological adjustment on gender-related stress

<i>BSI-18 → EAC → STSS</i>	<i>B</i>	<i>SE</i>	<i>Z</i>	<i>p</i>
Direct effect	.71	.09	8.05	.00
Indirect effect	.13	.05	3.00	.00
<i>BSI-18 → EAC → UCS</i>				
Direct effect	.17	.02	7.67	.00
Indirect effect	.02	.01	2.24	.03
<i>CD-QOL → EAC → STSS</i>				
Direct effect	-.30	.07	-4.28	.00
Indirect effect	-.09	.04	-2.33	.02
<i>CD-QOL → EAC → UCS</i>				
Direct effect	-.10	.02	-5.55	.00
Indirect effect	-.01	.01	-1.93	.05

Note. For analyses of BSI-18, $N=406$. For analyses of CD-QOL, $N=344$. UCS-R=Unmitigated Communion Scale-Revised; STSS=Silencing the Self Scale; EAC=Emotional Approach Coping Scale; BSI=Brief Symptom Inventory; CD-QOL=Celiac Disease Quality of Life Scale

Moderation analyses. Mplus 7.4 was used to perform moderation analyses. As was the case with mediation analyses, demographic variables were included as covariates (same variables as above). Results did not differ with and without covariates in any of the following models, so results without covariates are displayed below for simplicity.

Hypothesis 3c. First, social receptivity (SRS) was tested as a moderator of the effects of emotional approach coping on psychological adjustment. Contrary to hypotheses, social receptivity was not found to be a significant moderator of either

FEMINIST PERSPECTIVE CHRONIC DISEASE

outcome (see Table 10). In other words, the benefits of emotional processing and expression on psychological adjustment did not depend upon whether or not participants' rated their environment as socially receptive to talking about their difficulties with CD.

Table 10

Test of SRS as moderator of the effects of EAC on psychological adjustment

<i>BSI-18</i>	<i>B</i>	<i>SE</i>	β^*	<i>z</i>	<i>p</i>
EAC	-3.03	5.01	-.17	-.61	.55
SRS	-2.64	3.26	-.20	-.81	.42
EAC x SRS	.15	.22	.05	.12	.91

<i>CDQOL</i>	<i>B</i>	<i>SE</i>	β^*	<i>z</i>	<i>p</i>
EAC	1.13	5.00	.05	.23	.82
SRS	5.64	3.18	.34	1.77	.08
EAC x SRS	-.09	1.27	-.02	-.07	.95

Note. *N*=344. SRS=Social Receptivity Scale; EAC=Emotional Approach Coping Scale; BSI=Brief Symptom Inventory; CD-QOL=Celiac Disease Quality of Life Scale; EAC*SRS=Interaction Term

Hypothesis 5. Next, emotional approach coping was examined as a possible moderator between gender-related stress variables and psychological adjustment. Contrary to hypotheses, emotional approach coping was not found to be a significant moderator of either outcome (see Table 11). In other words, emotional processing and expression did not attenuate the negative effects of gender-related stress (i.e., prioritizing others' needs and silencing one's thoughts and opinions in order to maintain connection) on psychological adjustment.

Table 11

Test of EAC as moderator of the effects of gender-related stress on psychological adjustment

<i>STSS and BSI-18</i>	<i>B</i>	<i>SE</i>	β^*	<i>z</i>	<i>p</i>
STSS	.42	.13	.69	3.29	.00
EAC	3.93	3.74	.23	1.05	.29
STSS x EAC	-.03	.05	-.15	-.67	.51
<i>STSS and CDQOL</i>					
STSS	-.14	.15	-.19	-.92	.36
EAC	2.50	4.66	.12	.54	.59
STSS x EAC	-.03	.06	-.12	-.55	.59
<i>UCS and BSI-18</i>					
UCS	1.49	.53	.65	2.79	.01
EAC	5.10	5.36	.29	.95	.34
UCS x EAC	-.23	.19	-.41	-1.19	.23
<i>UCS and CDQOL</i>					
UCS	-.21	.56	-.08	-.38	.71
EAC	8.51	6.24	.40	1.36	.17
UCS x EAC	-.24	.21	-.36	-1.16	.25

Note. $N=344$. EAC=Emotional Approach Coping Scale; UCS=Unmitigated Communion Scale-Revised; STSS=Silencing the Self Scale; BSI=Brief Symptom Inventory; CD-QOL=Celiac Disease Quality of Life Scale; STSS*EAC and UCS*EAC =Interaction Terms

Post-hoc Analyses

Mediation and moderation. Following prior research suggesting that emotional approach coping consists of two distinct processes (emotional processing and emotional expression), and that emotional expression may have greater utility in predicting healthy outcomes (e.g., Stanton et al., 2000b), the emotional expression subscale of EAC was tested in all mediation and moderation analyses using EAC. Results did not differ from those using the overall score; emotional expression was not found to mediate or moderate the effects of gender-related stress. Furthermore, social receptivity was not found to moderate the effects of emotional expression.

FEMINIST PERSPECTIVE CHRONIC DISEASE

Linear regression. In order to examine the differential impact of unmitigated communion, self-silencing, emotional approach coping and demographic variables on adjustment-related outcomes, linear regressions were performed on psychological distress and disease-related quality of life. Analyses were performed using Mplus 7.4 and an online statistic calculator to determine F and p values for R^2 . Prior to these analyses, a composite variable was created to represent Celiac Disease-related symptoms. Because Celiac Disease symptoms can vary between and within individuals depending upon exposure and reactivity to gluten, severity and frequency were combined into one score. More specifically, severity and frequency ratings were multiplied to create an interaction term.

First, adjusted-related outcome variables were regressed simultaneously on all demographic variables (age, income, education level, length of time since diagnosis, symptoms, additional autoimmune disease diagnoses) and criterion variables (unmitigated communion, silencing the self, emotional approach coping). Income was identified as an important predictor of psychological distress that should be controlled for. Unmitigated communion, silencing the self, length of time since diagnosis and symptoms were also identified as important variables to be included in models of each outcome variable.

Results for the final models can be seen in Tables 12 and 13 below. Results in Table 12 demonstrate that after controlling for income, length of time since diagnosis, symptoms and gender-related stress predict 31% of variance in psychological distress ($\Delta R^2 = .31$, $F(4, 350) = 46.77$, $p < .01$). Effect size was large ($f^2 = .45$). Taken together, income ($\beta = -2.03$, $p < .01$), length of time since diagnosis ($\beta = -. = -.01$, $p < .05$),

FEMINIST PERSPECTIVE CHRONIC DISEASE

symptom severity and frequency ($\beta = .54, p < .01$), unmitigated communion ($\beta = .40, p < .01$) and silencing the self ($\beta = .19, p < .01$) predict 43% of variance in psychological distress ($R^2 = .43, F(5, 344) = 51.90, p < .01$). Effect size was large ($f^2 = .75$).

Table 12

Model of psychological distress

<i>BSI-18</i>	<i>B</i>	<i>SE</i>	β^*	<i>z</i>	<i>p</i>
Income	-3.61	.66	-.35	-5.50	.00
R^2	.12		<i>F-statistic:</i> 48.81		.00
<i>BSI-18</i>					
Income	-2.03	.54	-.20	-.375	.00
Time since diagnosis	-.01	.01	-.12	-2.31	.02
Symptoms	.54	.09	.26	5.91	.00
UCS-R	.40	.14	.17	2.90	.00
STSS	.19	.04	.30	4.40	.00
R^2	.43		<i>F-statistic:</i> 51.90		.00
ΔR^2	.31		<i>F-statistic:</i> 46.77		.00

Note. $N=350$. Time since diagnosis is in months; Symptoms=severity x frequency, each on a 1 to 5-point scale; UCS=Unmitigated Communion Scale-Revised; STSS=Silencing the Self Scale; BSI=Brief Symptom Inventory

Results in Table 13 demonstrate that length of time since diagnosis, symptoms and gender-related stress predict 29% of variance in disease-related quality of life ($R^2 = .29, F(4, 345) = 35.23, p < .01$). Effect size was large ($f^2 = .41$). Length of time since diagnosis in months ($\beta = .05, p < .05$), symptom severity and frequency ($\beta = -.56, p < .01$), unmitigated communion ($\beta = -.53, p < .01$) and silencing the self ($\beta = -.09, p < .05$) are significant predictors of disease-related quality of life.

FEMINIST PERSPECTIVE CHRONIC DISEASE

Table 13

Model of disease-related quality of life

<i>CDQOL</i>	<i>B</i>	<i>SE</i>	β^*	<i>z</i>	<i>p</i>
Time since diagnosis	.05	.01	.32	4.87	.00
Symptoms	-.56	.13	-.23	-4.34	.00
UCS-R	-.53	.16	-.19	-3.41	.00
STSS	-.09	.05	-.12	-1.98	.04
<i>R</i> ²	.29		<i>F-statistic: 35.23</i>		.00

Note. *N*=350. Time since diagnosis is in months; Symptoms=severity x frequency, each on a 1 to 5-point scale; UCS=Unmitigated Communion Scale-Revised; STSS=Silencing the Self Scale; CDQOL=Celiac-Disease Quality of Life Scale

Summary

In sum, these results demonstrate that greater levels of gender-related stress are associated with increased psychological distress and poorer quality of life in women with Celiac Disease. In other words, the more that women place others' needs before their own and silence their thoughts, feelings and opinions in order to maintain connection with others, the more distressed they are by the limitations, health concerns and treatment associated with their illness. Although these effects are not explained or buffered by differences in coping through emotional approach, the results demonstrate that women who process and express emotions surrounding disease-related interpersonal stressors are more well-adjusted. More specifically, these women report fewer anxious, depressive and somatic symptoms, feel less limited by their disease, have fewer health concerns and are more satisfied by the available treatments for CD.

Surprisingly, there is some evidence to suggest that increases in distress and reductions in quality of life may actually predict less coping through emotional approach, and that this may reinforce and increase gender-related traits and relationship schemas. This finding is surprising in light of prior research and theory that suggests relationships

FEMINIST PERSPECTIVE CHRONIC DISEASE

should flow in the opposite direction; that is, gender-related stress should predict decreases in emotional approach coping, which should increase distress and reduce quality of life. In addition to these findings, exploratory post hoc analyses demonstrate the combined importance of gender-related stress and disease-specific variables (length of time since diagnosis, symptom severity and frequency) in predicting psychological adjustment to CD.

The wide range of income levels, education levels and employment statuses of the women involved in the present study provide strong support for the generalizability of these results. Household income varied greatly, including a significant number of women with an income less than \$30,000 as well as a large number with an income of \$150,000 or higher. This is significant because a diagnosis of CD can require specialists and expensive medical tests, and therefore research samples can be skewed to include more individuals with greater household income and access to care. Thus, the present sample may more accurately reflect the overall population of women with the disease. The wide variety of education and employment status also provides support for this idea, capturing a wide range of lifestyles and abilities. The sample was also relatively representative of the broader population in terms of race and ethnicity. CD is much more prevalent among those of European descent, and this was reflected in the present sample (93.2% white). However, it is important to note that without representation of other races and ethnicities, it is difficult to draw conclusions about the impact of CD across cultures that may have different traditions around food and cuisine.

Chapter 5: Discussion

The following chapter will summarize and interpret the findings of the present study within the context of relevant literature. More specifically, it will examine: (1) the role of gender-related stress in disease adjustment; (2) the role of emotional approach coping in disease adjustment, including relationships with gender-related stress, the relevance of perceived social receptivity and the distinction between emotional processing and emotional expression; and (3) exploratory models of disease-related adjustment. Finally, it will discuss study limitations and considerations for future research.

Gender-Related Stress

Consistent with expectations, gender-related stress was found to be an important predictor of adaptation to Celiac Disease. Both unmitigated communion and self-silencing were positively associated with psychological distress and negatively associated with multiple aspects of disease-related quality of life. These results provide support for the idea that the more a woman prioritizes the needs of others and/or withholds her emotions, opinions, strengths and capabilities in order to maintain relationships, the more difficulty she is likely to have in adjusting to the interpersonal stress associated with CD. This is not surprising considering how unmitigated communion has previously been associated with lower levels of self-advocacy, more negative social interactions and more negative affect in response to relationship stress in other samples of women with chronic illness (Brody et al., 2014a; Helgeson, 2003; Helgeson & Fritz, 1999; Trudeau, Dannoff-Burg, Revenson, & Paget, 2003). Furthermore, this is consistent with prior research that

FEMINIST PERSPECTIVE CHRONIC DISEASE

demonstrates associations between self-silencing and decreased self-care and adherence to treatment (Kayser, Sormanti, & Strainchamps, 1999; Brody et al., 2014b).

Lower levels of self-advocacy, negative affect in response to relationship stress and decreased self-care may be especially damaging in the context of CD-related stressors. When asked to describe the most interpersonally stressful aspect of their disease, women in the present study touched frequently on these issues, citing difficulties with things such as inconveniencing or offending others, asking too much and/or feeling judged or excluded because of their dietary needs. For example, one woman stated, “I feel torn between not wanting to get sick and not wanting to ask too much of my new family member who has not yet had to cook for someone with Celiac Disease.” Another said, “The most stressful interpersonal aspect is determining when to assert my needs when interacting with others... I don’t want to feel like I’m preventing others from eating somewhere they really want to, just because it is not a good place for me to eat. There is a tension between wanting my diet to be acknowledged, but not having everything revolve around it.” As is demonstrated by these two examples, many women with CD grapple with interpersonal stressors that have a tendency to involve excessive concern about others’ needs, leading to distress and increased interference with quality of life.

The intersection of gender-related stress and interpersonal-stress demonstrated by the women’s narratives highlights a possible need for increased agency among women with CD. Agency, defined by Helgeson as a focus on or orientation towards the self, is more typically associated with the male gender role (e.g., Helgeson, 1994). Considering that men with CD are significantly less likely to report that their disease interferes with their social activities (68% to 17% in one study; Lee, 2012), it is possible that an

FEMINIST PERSPECTIVE CHRONIC DISEASE

orientation towards the self that prioritizes one's own needs may serve as a buffer to the interpersonal stress described by women in the present study. If this is indeed the case, interventions that encourage a healthy focus on and assertion of one's needs may be warranted.

Emotional Approach Coping

Relationship to gender-related stress. Consistent with hypotheses, gender-related stress was negatively associated with emotional approach coping. Although little to no prior research has examined relationships between these constructs, theory provides strong support for this finding. EAC requires a focus on the self and dependence upon others to help take care of one's needs. Thus, it intuitively follows that an increase in gender-related stress, which reduces a focus on the self and interferes with a healthy dependence upon others, would result in a decrease in EAC.

In the present study, women were asked to report situational emotional approach coping, or how frequently they process and express their feelings when managing what they believe to be the most stressful interpersonal aspect of living with CD. As was mentioned above, the most stressful interpersonal elements reported by many women in the study related to aspects of gender-related stress, such as struggles with self-advocacy, potential for negative relationship events and treatment adherence in complex social situations. Common responses included recurring stressors such as, "explaining and advocating for my dietary needs in new social situations," "being unable to feel comfortable eating at so-and-so's house [because they are unable to make gluten-free food]" or "getting sick from eating at so-and-so's house and not being sure how to tell them." Measuring EAC in women with CD in this context provides further support for

FEMINIST PERSPECTIVE CHRONIC DISEASE

how the presence of gender-related stress may make it especially difficult for women to utilize this strategy in these types of recurring situations. While many of the stressors that the women described reflect maladaptive gender-related traits and relationships schemas, they also highlight a pervasive inability or discomfort with focusing on one's own feelings and depending upon others to take care of one's emotional needs. In addition to illuminating how gender-related stress might give rise to distress in difficult interpersonal situations, the women's narratives suggest how it may also impede one's ability to self-reflect and utilize others for support, two essential processes for healthy coping through emotional approach.

Relationship to psychological adaptation. Given the negative associations between gender-related stress and EAC in response to CD-related interpersonal stress, it is not surprising that EAC was positively associated with psychological distress and negatively associated with multiple aspects of disease-related quality of life. This is consistent with research done in samples of women with chronic myofascial pain, fertility treatment and breast cancer, where EAC has been associated with lower levels of pain, distress and depressive symptoms and higher levels of self-reported physical health, vigor and survival (Reynolds et al., 2000; Smith, Lumley & Longo, 2002; Stanton et al., 2000b). Thus, the present study provides further support for the utility of EAC in women's adjustment to chronic disease and in particular, the interpersonal stress associated with it.

Role of social receptivity. Following work by Stanton and colleagues (2000b), the present study examined the impact of perceived social receptivity on the effectiveness of EAC. Contrary to expectations, no interaction was found. Considering that beneficial

FEMINIST PERSPECTIVE CHRONIC DISEASE

emotional processing and expression requires a receptive and supportive ear, this finding is surprising.

Curiously, the mean scores of social receptivity in the present study were slightly lower than that of Stanton and colleagues' sample of women with breast cancer. Women with CD were more likely to be neutral on items such as, "There are people I can count on whenever I want to talk about my experience with Celiac Disease," while women with breast cancer were more likely to agree. This may reflect a uniquely difficult aspect of living with CD. Lower scores on social receptivity suggest that women may feel as if they are unsure of who they can and should talk to regarding concerns about their illness. While visible, highly publicized and imminently life-threatening illnesses such as breast cancer may be more easily recognized and sympathized with, a complex, invisible and incurable autoimmune disease such as CD may be more difficult to explain to others and thus more likely to be the target of invalidation instead of support. Further, it may be that instrumental support, such as willingness to provide accommodations or change plans sensitive to one's dietary needs may be more a valuable type of social receptivity than an emotionally supportive ear.

Emotional approach coping as a mediator. Contrary to expectations, EAC did not significantly mediate the impact of gender-related stress on psychological distress or disease-related quality of life. This is unexpected, especially considering that individual relationships among gender-related stress, EAC and outcomes were of the expected magnitude and in the expected direction.

It is possible that the presence or absence of other coping strategies may better explain the relationship between gender-related stress and adjustment to CD. This is

FEMINIST PERSPECTIVE CHRONIC DISEASE

supported by the fact that on average, women in the present study reported using EAC less than other groups, including community samples (e.g., Stanton et al., 2000a) and samples of women with breast cancer (e.g., Stanton et al., 2000b). One explanation may be that unlike most forms of cancer, CD is generally non-life threatening. Despite the fact that the only treatment, a lifelong gluten-free diet, places a large burden upon the patient and her support system, it is also almost always successful in managing symptoms and related health concerns. Because of CD's relative permanence and controllability, the difficult feelings associated with the diet and its limitations may be especially stable over time. Thus, relative to illnesses with a more temporary burden associated with higher stakes, there may be limited need for additional processing and minimal benefit in repeatedly expressing the same feelings.

Another, related explanation is that other forms of coping may be more beneficial. This idea is prevalent in women's narratives. For example, one described her most stressful interpersonal concern as, "I don't like to be the one that dictates where everyone HAS to eat in order for me to be able to participate." Another reported, "I don't like it when no one thinks about gluten-free options, but I also feel uncomfortable when other people make a big deal about finding a gluten-free restaurant or finding something for me to eat." It may be that EAC alone is not enough in these situations; they may also require problem-solving strategies, such as calling a restaurant ahead of time, or making more direct demands for support, such as communicating practically to friends what one needs in order to be able to participate. In addition to its negative impact on EAC, gender-related stress may also interfere with problem-focused strategies because even though

FEMINIST PERSPECTIVE CHRONIC DISEASE

they do not require communicating one's feelings, they do require advocating for one's needs even when they may be an inconvenience to others.

Due to the lack of temporal relationship between gender-related stress, EAC and outcomes, mediation analyses were also performed in the reverse direction, using outcome variables as predictors and vice versa. When tested in this fashion, EAC significantly mediated relationships between psychological distress and unmitigated communion, psychological distress and self-silencing, disease-related quality of life and unmitigated communion and disease-related quality of life and self-silencing. One possible explanation for these findings may have to do with the severity of disease. It is possible that women with more severe clinical presentations of CD, who have poorer quality of life and greater psychological distress, experience more intense levels of grief that cause coping burnout and withdrawal in both the patient and her support system. Corresponding decreases in EAC may serve to reinforce and strengthen relational traits and schemas associated with putting others' needs first and silencing oneself in order to maintain connection. In other words, the more a woman views her disease as a burden, the more important it may be to protect others from this emotional load in order to maintain relationships. Given that CD is a lifelong illness, this may be especially significant.

Emotional approach coping as a moderator. Also contrary to expectations, EAC did not moderate relationships between gender-related stress and psychological adjustment. Thus, the results from the present study suggest that using EAC in response to disease-related interpersonal stressors does not buffer women from the negative effects of putting others first and/or silencing their own voice. There are several potential

FEMINIST PERSPECTIVE CHRONIC DISEASE

explanations for the lack of a significant interaction. First, as was previously mentioned, women in the present sample rated the social receptivity of their environment as lower than those in prior research. This prior research suggests that social receptivity is essential for EAC to be effective (e.g., Stanton et al., 2000b), so it may be that on average, women with CD who attempt to process and express their emotions are more likely than other groups to receive invalidating, or unhelpful responses.

It may also be the case that the need for problem-focused strategies in healthy adaptation is obscuring this relationship. Rather than examining EAC as a buffer to gender-related stress, problem-focused strategies may be more important. These strategies require a woman to adeptly advocate for her own needs as well as seek sources of instrumental support in challenging social situations. Indeed, research shows that problem-focused coping is more common among men with CD, and that it may help to explain gender-related differences in quality of life (e.g., Hallert, Sandlund, & Broqvist, 2003).

Processing versus expression. Prior research examining EAC in chronic illness has highlighted the importance of two separate processes: emotional processing and emotional expression. While many studies have found overall scores of EAC to be useful predictors of psychological adaptation to illness (e.g., Stanton et al., 2000a), others have found that a closer look at each subscale reveals a more nuanced picture. Although emotional processing and emotional expression have each been shown to be uniquely associated with positive outcomes (e.g., Berghuis & Stanton, 2002; Smith et al., 2002), in some studies emotional processing has also been shown to have no effect or even a negative effect when controlling for emotional expression (e.g., Stanton et al., 2000b).

FEMINIST PERSPECTIVE CHRONIC DISEASE

A closer look at emotional processing and emotion expression in the present study provides support for the idea that these are related, but separate processes. Not surprisingly, processing and expression were strongly correlated with one another. Relative to expression, processing had weaker relationships with gender-related stress. While expression was associated with reduced psychological distress and increased disease-related quality of life, processing had no relationship with either outcome. This is consistent with some of the literature that suggests that emotional processing, while important for healthy coping, is not sufficient (e.g., Stanton et al., 2000b). Emotional expression, or taking what one has processed and sharing it with others in exchange for support, is an essential next step that may explain the benefits of EAC. In women with CD who must navigate considerable interpersonal stressors, this component may be especially predictive of successful adaptation.

Exploratory Models of Disease-related Adjustment

Due to the exploratory nature of this study as the first to measure gender-related stress and EAC in Celiac Disease, post hoc analyses were performed in an attempt to build a preliminary model of psychological adjustment to CD. While the focus of these models was on factors pertinent to gender and disease-related stressors, demographic variables were considered as possible covariates. Because of its moderately strong relationship with the BSI-18, income level was included in the model of psychological distress. This was in line with prior research which demonstrates relationships between income level and mental health outcomes (e.g., Caron & Liu, 2011). Because income level had a weak relationship with CD-QOL scale, it was not included in the model of disease-related quality of life.

FEMINIST PERSPECTIVE CHRONIC DISEASE

After simultaneously regressing psychological distress and disease-related quality of life on selected disease-related demographic and criterion variables, several important influences on disease-related adjustment were identified. The pertinence of gender-related stress, disease-related factors and emotional approach coping in models of psychological distress and disease-related quality of life are discussed, in turn, below.

Gender-related stress. Given the large body of research that supports the importance of gender-related stress in women's adjustment to chronic illness, it is not surprising that measures of unmitigated communion and self-silencing were found to be predict unique variance in both psychological distress and disease-related quality of life in CD. Importantly, these findings held even when controlling for pertinent demographic and disease-related factors. Thus, these exploratory models provide further evidence of the negative effects associated with prioritizing others' needs and silencing one's thoughts, feelings and opinions in order to maintain connection when faced with disease-related interpersonal stress.

Disease-related factors. Two disease-related factors were found to be unique predictors of psychological distress and disease-related quality of life: length of time since diagnosis, and symptom severity and frequency.

Length of time since diagnosis. The length of time since diagnosis varied greatly among women who completed the survey, ranging from less than one year to over 70 years ($M = 7.73$ years; $SD = 1.31$). This variability is essential because interpersonal stressors and one's response to them may vary depending upon the amount of time one has had to adjust to them. Not surprisingly, this study is not the first to suggest that length of time since diagnosis is an important predictor of psychological adaptation to illness.

FEMINIST PERSPECTIVE CHRONIC DISEASE

This finding is consistent with other research pointing to an increased knowledge of and ability to navigate the gluten-free diet over time, as well as a corresponding improvement in symptoms (e.g., Hallert et al., 1998; Lee et al., 2012). In light of the present research, it is also possible that as more time passes since diagnosis, individuals with CD become savvier navigators of interpersonal stressors associated with the disease.

Symptom severity and frequency. It is also not unexpected that symptom severity and frequency are important factors in predicting psychological distress and disease-related quality of life. Unlike some other chronic illnesses, the severity and frequency of symptoms vary greatly both within and between individuals with CD. Each individual's reaction to gluten is unique in nature and severity, and can include anything from gastrointestinal discomfort to severe headaches and fatigue. Furthermore, the disease is frequently accompanied by other chronic health conditions, such as anemia and/or autoimmune disease (in the present study, 39.7% had least one additional autoimmune disease diagnosis) that worsen with gluten exposure but are present regardless of whether or not it has occurred. Considering the great variability in sensitivity to gluten, frequency and severity of symptoms, it is important to recognize the vast heterogeneity of presentations among women living with CD. While some women might have extremely intense adverse reactions to gluten, they may not have as significant of an impact on their quality of life as compared to other women with less intense symptoms that persist even in the absence of gluten exposure. In sum, both severity and frequency matter, and should be taken into account when considering distress and disease-related quality of life. It will be important to consider ways to look at each of these variables together as well as

separately, including investigating the psychometric properties of symptom measurement that takes both factors into account.

Emotional approach coping. Considering the positive benefits associated with EAC in studies of women with other chronic health conditions (e.g., Berghuis & Stanton, 2002; Reynolds et al., 2000; Smith, Lumley, & Longo, 2002; Stanton et al., 2000b), the absence of EAC in these models is noteworthy. In addition to illuminating the relative importance of gender-related stress and pertinent demographic factors such as length of time since diagnosis, this finding also highlights the relative importance of EAC compared to other forms of coping in CD. As has been previously mentioned, due to the nature of its symptoms and treatment, CD may require more problem-focused coping and instrumental support than other chronic illnesses with less direct interpersonal stress. Prior research has provided support for this hypothesis, demonstrating negative effects of emotion-focused coping in CD (Dorn et al., 2010; Smith & Goodfellow, 2011) and suggesting that men with the disease may have better outcomes because of their ability to use more problem-focused coping strategies (Hallert, Sandlund, & Broqvist, 2003).

Limitations

There are several limitations of the present research. Methodological issues and concerns about participant sampling and drop out will be described, in turn, below.

Method. One of the most important drawbacks of the study's design is the reliance on self-report at one point in time. One concern is that this may have introduced shared variance and inflated correlations between gender-related stress variables, EAC and adjustment-related outcomes. Another concern is that this may have limited the ability to capture disease-related processes that fluctuate over time. Symptoms and

FEMINIST PERSPECTIVE CHRONIC DISEASE

distress in CD can be heavily dependent upon whether or not one has recently been exposed to gluten. Therefore, it is possible that some participants who had been recently exposed may have responded in a way that is atypical of them when they are feeling well. Likewise, participants without recent exposure may have responded in a way that does not reflect how they feel when experiencing disease-related symptoms. With data collection at only one time point, it is difficult to differentiate whether participants' responses were influenced by their current CD-related health.

In addition to these methodological concerns, another drawback of the study design is the lack of temporal relationship between variables. True mediation analysis requires that the independent variable, mediator and outcome variable be measured at different time points in order to determine causality. Without a temporal relationship, this research is limited in its ability to draw conclusions about the directionality of relationships and it is difficult to make claims about mediation results. Especially considering that significant mediation was found in the opposite direction of expectations, research with data collection at multiple time points is essential.

Sampling. Another important methodological aspect that may limit the generalizability of results is the recruitment method. Most participants were recruited through posts on community boards, support websites and support list serves. Thus, the sample largely consists of women who are actively involved in the CD community. This may have skewed results in multiple ways. First, although scores on the BSI-18 and CD-QOL measures were representative of CD samples in other studies, it is possible that women who engage with support websites and groups may be more likely to be distressed by and to report disease-related interpersonal stressors. Furthermore, women

FEMINIST PERSPECTIVE CHRONIC DISEASE

who engage with these networks in order to help others may be more likely to prioritize others' needs before their own, or silence themselves in order to maintain connection. Indeed, scores on the Silencing the Self Scale were higher than other clinical and community samples, such as one of women with irritable bowel syndrome and one of healthy women.

Also of note, participation in the present study required access to and ability to use a computer. Although the sample was diverse in terms of household income, this requirement may have limited recruitment of individuals with lesser means. Thus, women who represent an important demographic of those with CD – namely, those with fewer resources for navigating and coping with the illness and its treatment – were possibly underrepresented.

Dropout. Finally, another key limitation of the present study concerns participant drop out. While 406 participants gave informed consent, 62 dropped out after providing disease-related demographic information and prior to completing the first outcome measure (CD-QOL). Ten more dropped out prior to completing the next measure (BSI-18) and 15 more stopped prior to completing the first assessment of gender-related stress (UCS-R).

The greatest drop out point occurred when filling out the Silencing the Self Scale (35 participants), which came next. This scale is the last measure before participants were asked to describe the most stressful interpersonal aspect of living with CD, and also the longest measure included in the study (31 items). It is possible that participants found this scale to be distressing because it asks several questions about maladaptive relationship schemas. Indeed, a few participants reached out to researchers regarding concerns that the

FEMINIST PERSPECTIVE CHRONIC DISEASE

study was making negative assumptions about women with CD. Thus, it is worth considering that individuals who dropped out at this point may have scored differently on survey measures than those who found them to be less distressing or more applicable to themselves.

Data was also missing for 26 additional participants on the Emotional Approach Coping Scale. This scale was administered immediately following qualitative responses about the most stressful interpersonal aspect of living with CD, so it is possible that individuals who were unable to identify such a stressor dropped out at this point, reducing variability in the measure of EAC. Finally, a significant number of participants did not complete general demographic measures, which were given at the end of the survey (e.g., 77 were missing for race/ethnicity, 87 were missing for household income). This is significant because without knowing the race, ethnicity or household income for a large proportion of participants, our ability to make conclusions about the generalizability of the sample is limited. However, this concern is attenuated by the fact that 1) women with CD are relatively homogenous in terms of race and ethnicity (i.e., predominantly Caucasian); and 2) our findings in regards to household income are similar to other research examining the effects of income on health outcomes.

Future Research

Given that the present study is the first of its kind in women with CD, there are several important areas for future research. Suggestions regarding longitudinal study, coping and gender-related stress will be discussed below.

Longitudinal study. As was previously mentioned, one of the biggest limitations of the present study was the measurement of all variables at one time point. As such, one

FEMINIST PERSPECTIVE CHRONIC DISEASE

of the most important directions for future research is that of longitudinal study, such as daily diaries. In addition to addressing the limitations associated with self-report at one point in time (such as insufficient temporal relationships for mediation analysis), this type of research would also help to identify the impact of interpersonal stressors associated with CD as they evolve with age and length of time since diagnosis. Although the present study successfully recruited women who varied greatly on these variables (e.g., age ranged from 18 to 84 years), data collection without multiple cohorts or time points is unable to capture many important processes, such as: a) changes in interpersonal stress associated with the disease over time; b) changes in coping strategy selection and effectiveness over time; c) age differences in the nature of interpersonal stress associated with the disease; d) age differences in coping strategy selection and effectiveness. For instance, how do interpersonal stressors and coping strategies change with age as one's social activities and obligations change? How do these variables shift after living with the disease and learning what "works"? While the present study demonstrates the importance of length of time since diagnosis for disease-related adjustment, it is unclear how each of these factors, or others, might explain this effect. Elucidating mechanisms by which improvement occurs over time is necessary in order to develop interventions that might accelerate this process.

In addition to these considerations, it is also important to recognize that difficult situations and gluten exposure do not occur to every woman with CD every day. Thus, assessment of criterion variables over time is essential in order to draw conclusions about their relevance. Furthermore, this type of research might help to tease apart the

FEMINIST PERSPECTIVE CHRONIC DISEASE

differences and interactions between symptom severity and frequency, which may uniquely impact psychological distress and disease-related quality of life.

Survey research. Given that many participants failed to complete the entire study, it will be important for future research to consider creative ways of avoiding attrition when delivering surveys. First, pertinent demographic information, such as race, ethnicity and household income, might be placed towards the beginning of the survey rather than at the end. This information is quick and easy for participants to respond to and carries great weight when examining results. In addition, future research might consider reminding participants that they may skip questions that they believe do not apply to them or cause any amount of distress. This was a common theme amongst responders in the present study, and likely contributed to drop out after gender-related and interpersonal stress measures.

Other methods of coping. Another important area for future research involves the selection and effectiveness of other coping strategies in managing interpersonal stress associated with CD. Although the present study successfully highlighted benefits of EAC, it also illuminated that it may not be sufficient for healthy adjustment. Given the propensity for CD symptoms and treatment to interfere with regular life activities such as meals and social activities, problem-focused coping and instrumental, rather than emotional, support may be necessary. Indeed, research shows that one of the possible reasons men with CD have better outcomes is that they are more likely to engage in problem-focused coping (Hallert, Sandlund, & Broqvist, 2003). One explanation for this may be that men typically show more agency, or focus on themselves and their own needs, than women do (Helgeson, 1994). Thus, future research would do well to examine

FEMINIST PERSPECTIVE CHRONIC DISEASE

the role of agency and problem-focused coping among women with CD as well as consider interventions that might increase use of these strategies. Assertiveness training, for example, has previously been suggested by other CD researchers (e.g., Leffler et al., 2008) and might be especially useful for women who struggle to find their voice or assert their needs. These women, who exhibit strong traits of unmitigated communion and relationship schemas of self-silencing, may desperately need to be more assertive in order to navigate their gluten-free dietary needs in social situations.

Gender-related stress. Finally, future research might look more closely at the ways by which we measure gender-related stress. To date, research has examined unmitigated communion and self-silencing as two distinct constructs. However, as is demonstrated in the present study, these two variables share variance in outcome measures and are highly correlated with one another ($r = .56$). Furthermore, close examination of the two measures reveals that many of the items might be interchanged with another. For example, “Even when exhausted, I always help other people” on the Unmitigated Communion Scale appears to tap a very similar construct to “One of the worst things I can do is be selfish” or “In a close relationship, my responsibility is to make the other person happy” on the Silencing the Self Scale. Thus, future research might consider examining all scale items simultaneously and making one cohesive, more unified measure of gender-related stress.

Future research might also consider ways by which to address strong participant reactions to these measures. In the present study, several participants wrote to the researcher to express that the gender-related stress measures did not describe them, and that their inclusion in the present research caused them distress. Future users of these

FEMINIST PERSPECTIVE CHRONIC DISEASE

scales might consider including a statement such as, “The following series of questions are meant to capture a wide variety of responses and reactions. Whether these questions apply to you or not, please answer as honestly as you can.” Alternatively, researchers might consider ways to shorten, or change the measures to include more positively worded items. For example, the item on the Silencing the Self Scale, “Doing things just for myself is selfish” might be reworded as, “I enjoy doing things for myself.”

Summary

The present study surveys a diverse, representative sample of women with Celiac Disease. It demonstrates the importance of gender-related stress variables in the generation and maintenance of interpersonal distress associated with CD among women. It also highlights the benefits of emotional approach coping and illuminates the significance of disease-related variables such as length of time since diagnosis and the interaction between symptom severity and frequency. It will be important for future research to employ longitudinal methods to further assess mediating relationships between gender-related stress and outcome variables, such as problem-focused coping. Although emotional processing and expression prove to be important, a better understanding of the effectiveness of behaviors requiring interpersonal agency might help to significantly inform potential interventions for more successful coping.

Appendix A: Literature Review

This literature review will focus on research relating to stress and coping in women with chronic disease using a feminist perspective. It will begin with information about the individual and societal implications of chronic disease, with an emphasis on interpersonal stressors and gender disparities in adjustment and experience. Next, it will introduce and explain how two feminist theories, unmitigated communion theory and relational-cultural theory, might help to make sense of gender disparities in adjustment, and critique the existing research utilizing each theory. It will then provide background on coping theory, with a focus on the gender-related coping strategy of emotional approach coping, and discuss research supporting its role as a potential mediator and/or moderator of relationships between gender-related stress and adjustment. Finally, pertinent research related to stress and coping with Celiac Disease, the disease of interest in the present study, will be discussed.

Chronic Disease and Adjustment

As of 2012, about half of all adults (117 million people) have one or more chronic health condition (Ward et al., 2014). Taken together with individuals diagnosed with mental health conditions, these individuals with chronic disease report an average of 32.1 more role-disability days in a given year than demographically matched controls, during which they are unable to carry out their usual daily activities as a result of their health (Merikangas & et al., 2007). This takes a significant toll on society, as evidenced by the CDC's report in 2014 documenting that 84% of all healthcare spending in 2006 was for 50% of the population who have one or more chronic conditions (CDC, 2014). Clearly, this significant interference with daily functioning can be a significant burden for

FEMINIST PERSPECTIVE CHRONIC DISEASE

individuals carrying one or more chronic health condition as well as for society in general.

Interpersonal implications of chronic disease. Given the significant toll that chronic disease can take, it is not surprising that it is related to negative psychological and social consequences that are associated with greater distress and poorer quality of life (e.g., Ciaramella & Poli, 2001; Dickens, Chris, Linda, Clark-Carter, & Creed, 2002).

Chronic disease results in major activity limitations, including those associated with paid and unpaid work, social activities, hobbies and even basic functioning, such as eating and sleeping. Of particular importance to the proposed study, chronic disease is often associated with significant changes in interpersonal functioning that may be especially stressful. Individuals are often faced with changing social roles at work, home and with friends. For example, chronic disease may render an individual no longer able to complete previously easy tasks, take care of others, or participate in leisure activities with friends. When most adaptive tasks may require help from others, including emotional sustenance and practical aid, adaptation in this domain is crucial to adjustment. Unfortunately, just as relationships and social networks can be supportive and caring in response to one's illness, they also can be characterized by misunderstanding, disapproval and antagonism (Stanton, Revenson & Tennen, 2007).

Gender disparities in adjustment. General adjustment is most commonly defined as the presence or absence of diagnosed psychological disorder, psychological symptoms, or negative mood (Stanton, Revenson, & Tennen, 2007). Adjustment to chronic illness more specifically includes additional criteria, namely mastery of disease-related adaptive tasks, preservation of functional status, and perceived quality of life in

FEMINIST PERSPECTIVE CHRONIC DISEASE

several domains (Stanton, Collins, & Sworowski, 2001). Adjustment varies greatly across individuals and can be influenced by a variety of contextual factors, including culture, ethnicity, socioeconomic factors, social resources and interpersonal support, personality, cognitions and coping processes. Importantly, gender-related processes can also play a significant role. Indeed, research shows that women with chronic disease report significantly more difficulty with pain, symptoms, disability and psychological health than do men (e.g., Chapman, Perry, & Strine, 2004; Katz & Criswell, 1996; Keller & Henrich, 1999). Relative to men, women with chronic illness have a greater vulnerability to and prevalence of depressive disorders, higher levels of disease-related distress, lower levels of life satisfaction, and poorer quality of life (Chapman et al., 2004; Katz et al., 2003; Keller & Henrich, 1999; Simrén, Abrahamsson, Svedlund, & Björnsson, 2001).

Feminist Theory

Two feminist theories explain why it may be important to take into account the unique psychosocial development of women when considering gender disparities in adjustment to chronic disease. Both theories draw from social construction theory to point out the impact that social concepts such as femininity and masculinity can play in shaping and organizing appropriate behaviors, practices, identities, emotional experiences, needs and desires of both sexes. In traditional Western culture, femininity is linked to a focus on others and connectedness, with attributes such as gentleness, submissiveness, dependency, and emotionality, whereas masculinity is linked to a focus on the self and separation, with attributes such as ambition, dominance, self-reliance and rationality (Bem, 1974; Eagly, 1987; Spence, 1984; Spence, Helmreich, & Stapp, 1974). Gender role theorists and social constructivists argue that the resulting social roles shape

FEMINIST PERSPECTIVE CHRONIC DISEASE

individual personality characteristics and the ways by which individuals define themselves (Brody, 1999; Eagly, 1987). While scholars more recently believe that feminine and masculine characteristics are orthogonal, with individuals of both sexes characterized by differing levels of each (for a review, see Spence & Helmreich, 2014), researchers have continued to show that women tend to score higher on measures of femininity whereas men tend to score higher on measures of masculinity (Helgeson & Fritz, 1999; 2000).

Emerging from these ideas, unmitigated communion theory and relational-cultural theory provide a means for us to understand women's uniquely relational experience and how this may influence their adjustment to disease. The first, unmitigated communion theory, describes a stable, trait-like orientation that many women develop as a result of their association with the traditional female gender role. The second, relational-cultural theory, describes how over time, women may develop certain cognitive schemas associated with maintaining relationships with others that are associated with the traditional female gender role. While the former represents a more stable personality trait and its associated behaviors, the latter represents more flexible cognitive schemas that guide behavior. Because each theory taps into unique sequelae of the female gender role, both will inform the proposed study and its selected measures. This section will review pertinent literature as well as critique existing research that has informed the present study.

Theory of Unmitigated Communion. Unmitigated communion theory stems from the basic idea that men and women have been socialized in different ways, which then impacts their health. One way that gender role socialization has been studied is by

FEMINIST PERSPECTIVE CHRONIC DISEASE

focusing on traits that are more common in one sex than the other, such as agency and communion (Spence, 1984). According to Helgeson (1994), agency and communion represent two fundamental ways of relating to the world: agency, which reflects one's existence as an individual and includes self-protection, self-assertion, self-expansion, self-control and self-direction, is more present among men; communion, which reflects the participation of the individual in a larger network and includes group participation, cooperation, attachment, and connections is more present among women (Helgeson, 2008).

The division of these traits as predominantly male and female oriented is supported by Eagly's (1987) social role theory, which states that sex differences in agency and communion stem from the traditional social roles that men and women hold in society – men's social roles are primarily agentic or instrumental in that they are the primary breadwinners of families; women's social roles are primarily nurturing or communal roles, as women take care of and raise children (Eagly, 1987). In line with Hyde's gender similarity hypothesis (Hyde, 2005), Eagly argued that gender differences are flexible; they are dependent on the immediate social role of individuals. For example, she found that homemakers, regardless of whether they were male or female, were perceived to be more communal and less agentic than people who held full-time jobs outside the home (Eagly & Steffen, 1984). While it is true that women are increasingly taking on agentic roles in addition to and instead of homemaking, Western society still implicitly and explicitly values women in communal roles and even judges against women in agentic ones (e.g., West et al., 2012). As a result, women tend to score higher

FEMINIST PERSPECTIVE CHRONIC DISEASE

on measures of traditional femininity, or communion, and men tend to score higher on measures of traditional masculinity, or agency (Helgeson & Fritz, 1999, 2000).

Agency and communion do little to explain sex differences in health. In fact, agency is related to positive health outcomes (e.g., positive mental health, fewer physical symptoms), while communion is related to positive, mutual relationships. What is troubling is when either agency or communion is present in the absence of the other. For example, communion, when unmitigated by agency, puts one at great risk for developing what is called unmitigated communion (UC; Helgeson & Fritz, 1999). UC is a personality orientation that is defined as a focus on others to the exclusion of the self, placing others' needs before one's own (Helgeson & Fritz, 1999). It is associated with lower self-esteem, over involvement with others and self-neglect. Individuals who score higher on measures of UC base perceptions of themselves on others' view of them, which leads them to fear negative evaluation by others. They are overly nurturing, intrusive and self-sacrificing and they may provide support to others to enhance self-worth (Helgeson, 1998). Women with higher levels of UC have difficulty asserting themselves, and even experience discomfort receiving support or engaging in self-disclosure (H. L. Fritz & Helgeson, 1998). Not surprisingly, this gender-related trait is higher in women than in men, and is associated with greater sensitivity to interpersonal stressors (Nagurney, 2007; Reynolds et al., 2006) as well as anxiety and depressive symptoms in community samples (e.g., Fritz & Helgeson, 1998).

Unmitigated Communion and health. A large body of literature demonstrates that the combination of over involvement with others and failure to attend to one's own needs is associated with poorer adjustment to chronic disease. Higher levels of UC

FEMINIST PERSPECTIVE CHRONIC DISEASE

predict anxiety and depression symptoms in adolescents with diabetes and adults with cardiac disease, rheumatoid arthritis, breast cancer and HIV (Brody et al., 2014a; Helgeson, 2003; Helgeson & Fritz, 1999; Trudeau, Dannoff-Burg, Revenson, & Paget, 2003). UC has significant interpersonal implications for female patients across medical conditions; it has been linked to lower levels of self-advocacy (HIV; Brody et al., 2014a), more negative social interactions (cardiac disease, breast cancer; Fritz, 2000; Helgeson, 2003) and more negative affect in response to relationship stress (diabetes and fibromyalgia; Helgeson & Fritz, 1996; Nagurney, 2008). Interpersonal stress associated with UC may even affect specific health outcomes. In one study of adolescents with diabetes, Helgeson and Palladino (2012) found that UC predicted poorer relationship quality and that this mediated the relationship between UC and poorer metabolic control.

The literature on unmitigated communion clearly demonstrates that an excessive focus on others might interfere with one's ability to manage aspects of one's health, and that this may negatively impact disease adjustment. It also reveals how an excessive focus on others can lead to undue stress in social interactions and relationships, which may also negatively impact disease adjustment. Both of these findings provide support for the assessment of the trait of unmitigated communion in the proposed study. The gap in the current literature, which the proposed study intends to address, is an understanding of how an excessive focus on others may interfere with interpersonal stress that is directly associated with having a chronic disease. As previously described, tremendous interpersonal difficulties can result from suffering with chronic disease. Without studying these interpersonal difficulties directly and within a feminist framework, our understanding of gender disparities in chronic disease remains incomplete. Thus, the

FEMINIST PERSPECTIVE CHRONIC DISEASE

proposed study intends to use an innovative, mixed methods approach to hone in on women's self-identified disease-related interpersonal stressors and to be the first to measure the impact of the female gender role on a woman's ability to cope with such stressors.

Relational-cultural theory. Another feminist theory that might help clarify the role of gender-related stress in disease adjustment is relational-cultural theory. Developed by feminist scholars in response to the gender-blindness of traditional models of psychosocial development, relational-cultural theory provides a framework within which to conceptualize the unique psychosocial development of girls and women (Jordan et al., 1991). Traditional Western theories of development focus on processes associated with masculinity. They emphasize agency as a part of healthy functioning; "mature" functioning is characterized by autonomy, separation and self-sufficiency (Jordan, 2001). Feminist scholars such as Gilligan (1988) and Jordan and colleagues (1991), however, have argued that the processes involved in the course of separation-individuation do not always fit for women and can cause significant distress.

Not unlike the aforementioned concept of communion, relational-cultural theory states that one of the primary goals of women's development is developing growth-fostering connections (Jordan et al., 1991). Women are thought to do so through the process of differentiation, within which relationships develop increasing levels of complexity, fluidity, and articulation (Jordan et al., 1991) as the individual develops one's own agency - talents, abilities and initiative - *within* the attachment (Jack, 1991). Relational-cultural theorists have identified four central characteristics of growth-fostering relationships: mutuality (as defined by perceived mutual involvement,

FEMINIST PERSPECTIVE CHRONIC DISEASE

commitment, and attunement to the relationship), authenticity (the process of acquiring knowledge of self and the other and feeling free to be genuine in context of relationships), empowerment/zest (the experience feeling personally strengthened encouraged, and inspired to take action), and the ability to deal with difference or conflict (Miller & Stiver, 1997). Since the inception of relational-cultural theory, research has documented the association between these characteristics and measures of well being; higher levels of relational health have been found to be correlated with lower levels of depression, perceived stress, and loneliness as well as increased self esteem (Liang et al., 2002). Empathic and validating connections with significant others are thought to allow individuals to develop and maintain realistic and stable self-esteem and self-efficacy, the capacity for self-regulation, a cohesive sense of self, and a connection to one's true thoughts, feelings and needs (Tantillo & Sanftner, 2010).

Given that cultural expectations and traditional models of psychosocial development seem to prioritize agency and separation, developing healthy interdependence may be exceptionally challenging for women (Jordan et al., 1991). When faced with disconnection, or interactions in relationships where mutual empathy and mutual empowerment do not occur, those who crave connection may be faced with what relational-cultural theory calls the "central relational paradox." This occurs when one alters herself or himself to fit in with the expectations and wishes of the other person in the relationship, and in the process, the relationship itself loses authenticity and mutuality, becoming another source of disconnection (Jordan, 2001; Miller & Stiver, 1997). This can be especially devastating, as evidenced by the fact that low levels of perceived mutuality in close relationships are associated with isolation, shame and

FEMINIST PERSPECTIVE CHRONIC DISEASE

depression; for example, research on eating disorders, a pathology that is more common among women than men, has found that lower levels of perceived mutuality have been associated with increased eating disorder psychopathology (e.g., Tantillo & Sanftner, 2010).

Self-silencing. Consonant with the relational-cultural paradox, Jack (1991) explained that some women internalize the idea that in order to develop and maintain intimate connections, they must engage in “self-silencing,” or a process of withholding emotions, opinions, strengths and capabilities perceived to be threatening to others. The construct of self-silencing emerged from Jack’s curiosity about women’s experience with depression. Familiar with Gilligan’s (1982) seminal works on the female “voice,” which argued for the differentiation of girls’ and women’s thoughts and feelings from men’s, Jack sought to explore these differences further in a relational context (1991). Akin to relational-cultural theorists, Jack noticed that women’s healthy capacity for intimacy has often been held up by Western culture as weakness. Using the example of “Susan,” one of her patients who felt that her need for a deep level of friendship or relationships was “sort of bad,” Jack (1991) writes the following:

We see how this woman’s healthy capacity for intimacy, a hallmark of adult maturity and health, has been held up to her by the culture as a weakness. Susan judges her feelings against a standard that says needing closeness makes one dependent, that one should be able to be self-sufficient and autonomous. She reflects upon her own experiences, her capabilities, and her needs not from the basis of who she is and what she wants, but in terms of how others see her (p. 5).

FEMINIST PERSPECTIVE CHRONIC DISEASE

Jack observed that depressed women tend to condemn themselves as “no good” or “worthless” on moral grounds, and believed that this moral language reflects cultural values and judgments about who women “should” be and how women “should” relate to others. Jack was referring to what other feminist scholars (e.g., Gilligan, 1982, 1988; Jack, 1991; Maine, 2001; Pipher, 1994) have also noticed: the strong social demands on women to be helping, pleasing, cooperative and self-sacrificing in relationships. Consequently, cultural and social role expectations set up a fundamental conflict for women. In order to fulfill the desire for connectedness, some women feel pressure to be “the good wife,” or “friendly and smiling all the time,” or “full of love and patience” (Jack, 1991, p. 7-8). But these women are also inevitably faced with times when their own needs, desires and feelings do not fit with these expectations (Jack, 1991), which can result in “self-silencing,” an active process of withholding emotions, opinions, strengths, and capabilities perceived to be threatening to the other in order to maintain the relationship (Jack, 1991, 1999). Although the goal of self-silencing is to maintain a sense of intimacy, harmony and connectedness with others, it actually creates disconnection and inauthenticity because parts of oneself are unknown to the other. Sometimes, women even experience a total loss of self, where they lose touch with their “voice,” including their thoughts, feelings and needs (Jack, 1991; 2011).

Research provides support for the idea that self-silencing schemas of how to create and maintain safe, intimate relationships may cause women distress (Jack, 2011). A large body of work has established associations between silencing the self and depression (Carr & Gilroy, 1996; Jack & Dill, 1992); as self-silencing increases, so does depression, and vice versa (Cramer, Gallant, & Langlois, 2005; Jack & Dill, 1992). Self-

FEMINIST PERSPECTIVE CHRONIC DISEASE

silencing has been shown to be important in understanding mental health disorders that are more prevalent among women, such as eating disorders. Withholding oneself from relationships to maintain connection has been strongly associated with internalization of the thin-body ideal, body image dissatisfaction, and disordered eating (Geller et al., 2000; Morrison & Sheahan, 2009; Piran & Cormier, 2005). Self-silencing may lead to inward displacement of negative feelings, such as anger, that may cause women to develop a poor body image and/or low self-esteem. Some women may go so far as to displace negative feelings onto their body, and engage in disordered eating as a coping or self-regulatory strategy (Schupak-Neuberg & Nemeroff, 1993). In sum, research suggests that the stress associated with withholding thoughts, needs and actions from others may negatively impact psychological health. Specifically, self-silencing may lead to a lost sense of self that contributes to low self-esteem and may even result in maladaptive self-regulatory behaviors, such as disordered eating.

Though the literature on self-silencing establishes that withholding thoughts and feelings from others is associated with poorer psychological health that may be the result of maladaptive coping with interpersonal stress, it is mostly descriptive, leading to very broad findings. Little research has examined the impact of self-silencing on women's responses to specific stressors. The proposed study hopes to address this limitation in the current literature by examining the experience of women in the context of a self-identified interpersonal stressor related to celiac disease. By using mixed methods, it will effectively take snapshots of women's experience with their most challenging interpersonal stressors to gain a deeper understanding of the influence of self-silencing schemas on women's experience than can be garnered from purely descriptive studies.

Relational-cultural theory, self-silencing and health. Despite its potential, very little work has utilized relational-cultural theory to understand chronic disease in a gendered context. In the few studies that have been conducted, self-silencing has been associated with decreased self-care (cancer; Kayser, Sormanti, & Strainchamps, 1999) and adherence to treatment (HIV; Brody et al., 2014b), providing support for this theory as a means for understanding gender differences in adjustment. No research to date, however, has utilized relational-cultural theory or the construct of self-silencing to better understand gender disparities in chronic disease adjustment. Given that traditional psychological theories and Western culture have been blind to the unique relational components of female psychosocial development, a critical next step to understanding women's difficulties with adjustment is to evaluate them within a gendered context. In combination with unmitigated communion theory, relational-cultural theory provides a necessary framework for understanding the potentially devastating consequences of chronic disease on interpersonal relationships. Specifically, the construct of self-silencing provides an important tool for measuring the impact of withholding emotions, opinions, strengths, and capabilities from others has on adaptive coping with interpersonal hurdles that emerge with chronic disease.

Coping Theory

The influence of gender-related processes on disease adjustment can be at least partially explained by taking a closer look at the stress and coping process. In particular, it will be important to use a feminist perspective to understand gender differences in exposure to and coping with disease-related stress. This section will explain the importance of focusing on interpersonal stress in the gendered context of chronic disease.

FEMINIST PERSPECTIVE CHRONIC DISEASE

Next, it will outline necessary background on coping theory, with a focus on the gender-related coping strategy of emotional approach coping, and discuss research supporting its role as a potential mediator and/or moderator of relationships between gender-related stress and adjustment.

Gender differences in stress. Gender is known to play a significant role in many aspects of the stress and coping process (Stanton et al., 2007). In general, women report experiencing stressors as more frequent and as more severe than do men (Helgeson & Tamres, 2002). Importantly, women also report experiencing more interpersonal stressors, or those involving relationships and social networks, than men (Helgeson, 2010). This may be particularly relevant to disease adjustment, where these types of stressors are especially prevalent and may even be exacerbated by the female gender role, which places such emphasis on connection and relationships. The toll that this may take is evidenced by a large Canadian survey study on gender differences in health, in which the authors argue that one reason for women's poorer health outcomes is their greater exposure to psychosocial stress in domains centered around taking care of and relating to others (i.e., personal, relationship, child, and family health; Denton, Prus, & Walters, 2004). Furthermore, preliminary qualitative research suggests that chronic illness may be especially devastating to women because of its impact on the female identity as a caretaker. For example, one study assessing diaries of sixteen middle aged women with chronic disease found that women struggled with the social constructions and expectations to place others' needs before their own; when they were unable to take care of others as a result of their illness, these women began to question their own self-worth

FEMINIST PERSPECTIVE CHRONIC DISEASE

(Kralik, 2002). From both broad survey and narrow qualitative studies like these, it is clear that women with chronic disease must face many unique challenges.

Significant empirical research supports the idea that interpersonal stress is a crucial determinant of health-related outcomes for women with chronic disease. Multiple studies provide evidence that interpersonal stress is associated with increased disease activity in rheumatoid arthritis, a disease more prevalent among women than men (Smith & Zautra, 2002; Zautra et al., 1997). Studying a disease more common among men, researchers who evaluated 187 women with coronary heart disease aged 30 to 65 found that marital stress was associated with a 2.9-fold increased risk of recurrent events (Orth-Gomér et al., 2000). Furthermore, additional research has associated interpersonal difficulties with delayed healing of wounds and accelerated emergence of the metabolic syndrome (Kiecolt-Glaser & et al., 2005; Troxel et al., 2005). A recent study by the National Institutes of Health sought to examine the biological underpinnings of the negative impact of social stress, examining 103 healthy young women. What they found not only corroborated the idea that chronic interpersonal difficulty, determined by a structured interview, was detrimental to health; they also found a potential mechanism to explain the excess morbidity associated with social stress in women, by way of accentuated expression of pro- and anti-inflammatory signaling molecules six months post-interview (Miller, Rohleder, & Cole, 2009). In summary, these studies demonstrate that women are especially vulnerable to interpersonal stressors, and that their health is likely to be adversely affected as a result.

Gender differences in coping. In addition to gender differences in the types of stressors that individuals face, there are also differences in the ways that men and women

FEMINIST PERSPECTIVE CHRONIC DISEASE

cope with stress (Folkman, 2010). Coping refers to the different strategies that we use to manage stressful events and the accompanying distress associated with them. A major distinction that has been made in the literature is between emotion-focused and problem-focused coping. Emotion-focused coping consists of “attempts to manage the internal reactions due to stressors, whereas problem-focused coping aims at altering or eliminating the stressor” (Lazarus & Folkman, 1984). Researchers frequently suggest that women are more likely to engage in more maladaptive, emotion-focused coping, while men are more likely to engage in more adaptive, problem focused coping. Some researchers suggests that these findings may be due to social role constraint – if women and men had equivocal social roles and thus faced more similar stressors, they would engage in more similar, problem-focused strategies, rather than emotionally-laden ones that result from their relationally-focused roles (Rosario et al., 1988). In a meta-analysis performed by Tamres, Janicki and Helgeson (2002), the authors point that women may engage in all coping strategies more than men because they tend to be more distressed than men. They also point out that women do consistently report greater relative use of emotionally laden strategies that involve expressions of feelings to others or to the self, but they are mixed in their adaptive quality: to seek emotional support, use positive self-talk and ruminate about problems. In summary, there appear to be differences in how men and women cope with stress, which tend to be more focused on emotions and may be the result of the female gender role.

Emotional approach coping. While emotion-focused coping has carried a bad reputation among many contributors to the coping literature for being associated with maladaptive outcomes, one group of prominent coping researchers have argued that

FEMINIST PERSPECTIVE CHRONIC DISEASE

emotional approach strategies, such as seeking emotional support and using positive-self talk, produce very different outcomes from emotional avoidance ones, like rumination (Austenfeld & Stanton, 2004). Thus, this group of researchers has proposed that emotional approach coping strategies may be a meaningful category for understanding how people, and especially women, engage with stressors in a proactive, pro-social and adaptive way.

Emotional approach coping (EAC) is an approach-oriented emotion-focused coping strategy that includes two levels: Emotion processing, which includes actively acknowledging and exploring emotions to come to an understanding, and emotion expression, which includes communicating one's emotional experience to others (Austenfeld & Stanton, 2004). Coping through these processes facilitates habituation to and labeling of emotions, cognitive reappraisal of stressors, clarification and pursuit of goals and strengthened social relationships (Stanton & Low, 2012). The two levels of EAC are thought to be most effective when used in sequence, and when used in response to interpersonal, uncontrollable stressors in a socially receptive environment (Stanton et al., 2000a; Stanton et al., 2000b). Following prior work by Stanton and colleagues (2000b), the proposed study will evaluate women's use of EAC in response to interpersonal, uncontrollable stressors and will assess for perceived social receptivity in each woman's life. It will examine emotion processing and emotion expression together as one total score, consistent with prior studies demonstrating results using this method (e.g., Smith, Lumley, & Longo, 2002).

Emotional approach coping and health. Substantial research has documented the effectiveness of EAC in women's coping with chronic illness. It has been associated

FEMINIST PERSPECTIVE CHRONIC DISEASE

with lower affective pain and depression symptoms in women coping with chronic myofacial pain (Smith, Lumley, & Longo, 2002), lower levels of distress in women suffering from failed infertility treatment (Berghuis & Stanton, 2002), and higher levels of self-reported physical health, vigor and survival in women with breast cancer (Reynolds et al., 2000; Stanton et al., 2000b). Despite an understanding that EAC is effective when used in response to interpersonal, uncontrollable stressors, and that it is associated with adaptive outcomes in the context of chronic disease, no research to date has examined EAC in the gendered context of disease-related interpersonal stress. EAC may be a particularly useful mediator and/or moderator of the relationship between gender-related stressors, such as traits of unmitigated communion and/or schemas of self-silencing, and adjustment outcomes. The importance of emotional approach coping to the present study will be discussed below, first as a potential mediator and second as a potential moderator.

Emotional approach coping as a mediator of gender-related stress. It is not surprising that a coping strategy that is effective in responding to interpersonal stress and involves expressing emotions to supportive others is one that commonly and effectively used by women in response to stress. Although women's more typical orientation towards connection may be one reason why EAC is generally so effective, this orientation may also interfere with the selection and effectiveness of this adaptive strategy. A greater focus on others and relationships, as understood by unmitigated communion and relational-cultural theory, may heighten some women's sensitivity to the impact of their health condition on their interpersonal relationships, and encourage self-neglect, self-criticism and self-silencing. Given that EAC depends upon processing

FEMINIST PERSPECTIVE CHRONIC DISEASE

emotions and *expressing them* to others, women who have been greatly affected by gender-related stressors may be less likely to choose this strategy as a means for coping and/or less likely to use it effectively. More specifically, a woman with high levels of unmitigated communion or self-silencing might be less likely to select or effectively use emotional expression as a coping strategy because of her fears about the consequences it might have for others or her relationships.

This idea is supported by two bodies of literature: (1) previously mentioned work that explains the mechanism of displacement in women with eating disorders from a relational-cultural perspective; (2) not yet mentioned literature that demonstrates how personality can influence coping strategy selection and effectiveness. The concept of displacement is crucial to understanding how, from a relational-cultural perspective, gender-related stress might prevent a woman from effectively processing and expressing her emotions. Displacement theory, which explains why some women exhibit eating disorder pathology, states that when women self-silence to preserve relationships, they may withhold from sharing negative thoughts and feelings that they internalize and displace onto their own body, simultaneously ignoring their feelings and damaging their sense of self worth (Schupak-Neuberg & Nemeroff, 1993). As an alternative coping strategy to processing and expressing emotions to others, disordered eating ensues. Thus, displacement provides just one example of how gender-related processes might facilitate poor adjustment.

A large body of literature on personality and coping supports the idea that a personality trait like unmitigated communion might influence coping strategy selection and effectiveness. Research has revealed evidence of consistency in coping strategy use

FEMINIST PERSPECTIVE CHRONIC DISEASE

across time and across stressful situations (Terry, 1994), and supports the idea that personality traits can be significant predictors of short and long-term coping styles. In particular, researchers have drawn connections between the big five personality traits (openness, conscientiousness, extraversion, agreeableness, neuroticism) and coping style. Neuroticism, which is characterized by a tendency to experience negative affect, has been associated with less perceived control in the context of social stress, and greater emotion-focused and avoidant coping responses in response to exclusion (Boyes & French, 2009). Extraversion, which is associated with a tendency to experience positive emotions and be warm, gregarious, fun-loving and assertive, has been related to social support seeking and negatively related to avoidance (Amirkhan, Risinger, & Swickert, 1995). Conscientiousness, which is characterized by being reliable, hard-working, and purposeful, has been associated with high use of problem-focused coping and low use of emotion-focused coping (Hooker, Frazier, & Monahan, 1994). Based on this type of evidence, some coping researchers have even suggested a model of coping that takes personality into account as a primary determinant (O'Brien & DeLongis, 1996). Taken together, this research suggests that coping styles may be at least partially dependent upon personality. Given that unmitigated communion is a stable personality orientation, it is reasonable to hypothesize that it might have an impact on women's coping strategy selection and effectiveness when faced with disease-related interpersonal stress.

Emotional approach coping as a moderator of gender-related stress. It is also important to consider that emotional approach coping may moderate the relationship between gender-related stress and adjustment. This hypothesis is based on an interactive or stress-buffering model in which stress has a detrimental impact depending on the

FEMINIST PERSPECTIVE CHRONIC DISEASE

degree of utilization of EAC. Considerable evidence supports the idea that coping may moderate relationships between stress and outcomes. For example, in a study of college students, Connor-Smith and Compas (2002) found that primary and secondary engagement coping strategies buffered the link between sociotropy, involving heightened concern about what others think and dependence on the approval of others for personal satisfaction, and anxiety/depression in the context of social stress, whereas disengagement coping augmented the relationship. In a follow-up study, the same researchers found that coping strategy selection may even moderate health outcomes: in a study of a separate sample of college students, they found that coping moderated relations between stress and heart rate reactivity and health status, with primary control engagement coping, secondary control engagement coping, and disengagement coping all serving as buffers (Connor-Smith & Compas, 2004). In sum, this research suggests that EAC may be an important buffer of the detrimental impact of disease-related interpersonal stress.

Chronic Disease of Interest: Celiac Disease

Many chronic illnesses, such as rheumatoid arthritis, fibromyalgia, breast cancer and multiple sclerosis are more frequent among women than men (Harbo, Gold, & Tintoré, 2013; Kvien et al., 2006; Yunus, 2002). These diseases take a significant psychological toll on women, which may be due to the considerable impact they have on interpersonal functioning and relationships. Given that interpersonal stressors more significantly affect women, and that interpersonal stress may be associated with women's poorer adjustment to the psychological and social consequences of chronic disease, it will be important to study an illness that: (1) disproportionately affects women; and (2) has a

FEMINIST PERSPECTIVE CHRONIC DISEASE

significant impact on social relationships, including necessary navigation of disease-related social interactions. These conditions allow us to learn more about the role of the gendered context in responding to the interpersonal consequences of chronic disease. Celiac Disease (CD), an autoimmune disorder characterized by impairing symptoms that are triggered by the consumption of gluten, generously meets these criteria. The following section will detail the epidemiology and treatment of Celiac Disease, including the significant psychosocial implications. Gender disparities in adjustment and experience will be discussed as they relate to the proposed study.

Epidemiology. Celiac Disease is common worldwide, currently known to affect approximately 1% of the total population including 0.71% or 226.5 million people in the United States – a number that is growing at an exponential rate (Ludvigsson et al., 2013; Reilly & Green, 2012; Rubio-Tapia et al., 2012). The disease occurs mainly in Caucasians, but has been growing in awareness and diagnosis among other ethnic groups (Reilly & Green, 2012). Celiac disease can be diagnosed at any age, and with a variety of clinical presentations. The major mode of presentation for adults is diarrhea and weight loss from autoimmune damage in the small intestine, though this occurs in less than 50% of patients, and does not always include those who can also present with anemia, reduced bone density, villous atrophy in the intestines, dermatitis herpetiformis, IBS, bloating, chronic fatigue, neurological symptoms or even no symptoms. Risk factors include family members with the disease, Type I diabetes and autoimmune liver disease (Reilly & Green, 2012). Diagnosis is made using blood tests for gluten autoantibodies and a small bowel biopsy to assess damage. Once affected, individuals with CD often continue to experience symptoms and are at risk for additional health problems, including other

FEMINIST PERSPECTIVE CHRONIC DISEASE

autoimmune disease such as Addison's disease, thyroid disease, dermatologic and rheumatologic disorders, infertility and osteoporosis (Choi et al., 2011; Denham & Hill, 2013; Fasano & Catassi, 2012; Midhagen & Hallert, 2003). In adults, CD is also known to be associated with increased rates of anxiety and depression (Smith & Gerdes, 2012). The only known treatment for Celiac Disease is a strict, lifelong gluten free diet.

Psychosocial aspects of Celiac Disease. Given that eating is often a social activity, the only treatment, a strict, lifelong gluten-free diet, makes CD a uniquely social disease. Indeed, eating is embedded within processes that give meaning to everyday lives, such as caring for and being cared by others (Delormier et al., 2009). Eating is one way by which people interact with one another, spend time together, and form relationships. As has been well documented in the eating disorders literature, one's feelings about eating and eating behaviors can be significantly impacted by interpersonal factors, such as family dynamics, peer pressure, the media and cultural norms (Calam et al., 1990; Lieberman et al., 2001; Neumark-Sztainer et al., 1999). Research on acculturation processes shows that individuals may change their attitudes about food and their eating behaviors to mimic those around them, even when the shift is an unhealthy one (Ball & Kenardy, 2002). Clearly, thoughts, feelings and behaviors related to eating are significantly intertwined with social factors.

Considering that the only treatment option for those with CD is a very specific diet that may make social interaction surrounding food especially challenging, the management of CD may give rise to excessive interpersonal stress. Everyday, those with CD are faced with decisions about how to procure food that is safe for their diet and/or whether to self-disclose their condition with individuals they do not know well. Often,

FEMINIST PERSPECTIVE CHRONIC DISEASE

these decisions lead those with CD to weigh whether participating in a social activity involving food is worthwhile at all. Not surprisingly, many studies support the idea that reduced quality of life in CD is largely the result of the interference of the disease and its associated treatment with social and leisure activities (Black & Orfila, 2011; Lorenzo et al., 2011; Zarkadas et al., 2013). Qualitative studies have revealed that diagnosis of CD is associated with a number of interpersonal stressors, including unwanted visibility and self-disclosure, feeling neglected or forgotten, and experiencing difficult emotions including isolation, shame and fear (Sverker, Hensing, & Hallert, 2005). No research to date, however, has attempted to define or quantify how these challenges, and ways of coping with these challenges, might be related to adjustment outcomes such as psychological health or disease-related quality of life.

Gender differences. Importantly, women represent approximately two thirds of the CD population (Megiorni et al., 2008). Relative to men with the disease, they consistently report more pronounced symptoms (Midhagen & Hallert, 2003), lower quality of life (Hallert et al., 1998, 2003; Zarkadas et al., 2006) and poorer psychological well-being (Roos et al., 2006) than men.

Research has begun to reveal why women with CD struggle significantly more than men. Women experience CD as having a greater disease burden associated with necessary dietary restrictions (Hallert et al., 2002) and some researchers have hypothesized that this is related to the female gender role. Sverker and colleagues (2009) suggest that for women with families, who work professionally and take care of family members in their household, CD imposes a “triple burden,” such that food-related CD activities take away from the little time left for oneself after paid and unpaid work is

FEMINIST PERSPECTIVE CHRONIC DISEASE

finished. Interviews, which highlight that women with CD experience significant distress due to the restrictions imposed upon socializing with friends (Lee et al., 2012), provide further support for the significance of the female gender role.

Limited research on coping with Celiac Disease highlights the need for a better understanding of gender differences in experience and adjustment. Hallert and colleagues suggest that women may perceive CD to be more burdensome because of their proclivity towards an emotion-focused coping style, relative to men's problem-focused coping style (2003). As we know from the coping literature reviewed above, women's tendency to focus on emotionally laden coping strategies may be related to their gender role and greater experience of relational or interpersonal stressors. We also understand that the domain of emotion-focused coping can be broken down into multiple subdomains, some of which are adaptive (i.e., emotional approach coping) and some of which are maladaptive (i.e., rumination; Austenfeld & Stanton, 2004). Approaching the study of how women cope with a highly interpersonally stressful disease like CD from a gendered perspective allows much more nuanced perspective of gender roles and gender-related stress on coping. Furthermore, doing so with an innovative mixed methods approach that allows stress and coping processes to be both described and quantified provides a unique means to draw connections between the existing qualitative literature, which highlights the plethora of interpersonal stressors associated with CD, and quantitative literature, which highlights women's greater symptoms, poorer quality of life, and tendency to use emotion-focused coping in the face of CD.

In summary, CD is a prime candidate within which to study the impact of gender-related stress associated with the female gender role. Celiac Disease is a uniquely social

FEMINIST PERSPECTIVE CHRONIC DISEASE

disease, with daily opportunities for tremendous interpersonal stress. Furthermore, this interpersonal stress is not only exacerbated by women's drive towards growth-fostering connection (which a highly restrictive diet may threaten), but is also potentially related to gendered processes (i.e., the "triple burden"). Despite these connections, the experience of women with CD has never been studied within a feminist framework. Furthermore, no study has attempted to understand how women cope with CD, as well as what the role of interpersonal relationships might be in bolstering or hindering their ability to cope.

Conclusion

Although research shows that women have significantly more difficulty with adjustment to chronic disease, few studies have examined this phenomenon within a gendered context. Two feminist theories, unmitigated communion and relational-cultural theory, demonstrate how the female gender role might introduce a unique set of interpersonal stressors that could greatly interfere with adjustment. Even though (1) these theories are well documented in the feminist literature to be associated with negative mental and physical health outcomes; (2) adjustment to disease is associated with a number of interpersonal stressors; and (3) women have unique ways of coping with stress that may be related to their female gender role, unmitigated communion theory and relational-cultural theory have yet to be studied in the context of coping with disease-related interpersonal stress. Celiac Disease is a prime candidate to study these processes within a feminist framework because (1) it disproportionately affects women; and (2) it has a significant impact on social relationships, including necessary navigation of disease-related social interactions.

Appendix B

Recruitment Documents and Informed Consent

Recruitment Documents

Online Advertisement

Are you a woman diagnosed with Celiac Disease? Do you attempt to follow a strict gluten free diet? Are you at least 18 years of age? If you answered “yes” to all of these questions, you may be eligible to participate in a study conducted by researchers at the University of Maryland. The study explores the experiences of women like you through a brief online survey. We want to learn directly from women with Celiac Disease about the experience of living with its unique challenges and restrictions. This your chance to contribute to research aimed at improving the experience of women with Celiac Disease.

The survey can be done online from anywhere that is convenient for you. It will take approximately 20-30 minutes of your time. This research is being conducted by Elizabeth Reeves, B. S. and Mary Ann Hoffman, Ph.D. at the University of Maryland, College Park. If you would like to participate in this research, please contact Elizabeth Reeves at ejreeves@umd.edu.

Email

Dear Participant,

Thank you for your interest in this study, which is being conducted by researchers at the University of Maryland, College Park. Your participation will contribute important knowledge regarding the experiences of women with Celiac Disease. This questionnaire will take most people approximately 20-30 minutes to complete. It is important that you answer all questions in one sitting, so if you are completing this questionnaire on your own, **please seek out a quiet place that is free from distractions** while taking the survey.

In order to better understand the experiences of women with Celiac Disease, it will be necessary to ask questions related to your background and current situation. Some of these questions may be personal in nature, including items inquiring about your income, relationship status, medical history, thoughts and feelings. Due to the personal nature of some of this material, it is important for you to know that the information you give **will be kept confidential**. You will not be asked for your name, and all information will be stored in a secure, locked location to which only the investigators have direct access. When analyzed, all survey responses will be evaluated as a group; no individual responses will be examined.

Risks associated with this study may include feeling discomfort in response to some content or inadvertently disclosing your responses if the survey is not taken in private. However, you do not have to answer any questions that make you feel uncomfortable. Benefits include the opportunity to reflect on your experience as a woman with Celiac Disease. Your participation in this study is **voluntary** and you may choose not to

FEMINIST PERSPECTIVE CHRONIC DISEASE




participate and may stop at any time. If you experience any difficulty in submitting your responses please contact the first researcher at the email address below.

If you have any questions or comments about the study, please feel free to contact either of the researchers (contact information below). If you have questions about your rights as a research subject, please contact the Institutional Review Board (also below). This research has been reviewed according to the University of Maryland, College Park IRB procedures for research involving human subjects. Thank you again for your participation. By giving your consent to participate, you indicate that **(1) you are a woman of at least 18 years of age; (2) you are diagnosed with Celiac Disease and attempt to follow a strict gluten free diet; (3) the research has been explained to you; (4) your questions have been fully answered; and (5) you freely and voluntarily choose to participate in this research project.** If you agree with these statements and consent to participate, please click on the 'Continue' button below.

Elizabeth Reeves, B. S.
Counseling Psychology Program
CHSE Department
University of Maryland
College Park, MD 20742

Mary Ann Hoffman, Ph.D
Professor, Counseling Psychology
CHSE Department
University of Maryland
College Park, MD 20742

Flyers



LIVING WITH CELIAC DISEASE?

Help other women who are too.

How?

A 20-30 minute survey about your experience with Celiac.

Answer questions about:


- How its symptoms and restrictions may interfere with your life
- How you cope with the challenges of the disease

Requirements

- Female
- At least 18 years old
- Diagnosed with Celiac Disease
- Strictly adhere to Gluten Free diet

Sign up!




VISIT THIS LINK: [insert link here]

Or SCAN THIS CODE: 

About the researcher:

Elizabeth Reeves is a Doctoral student in Counseling Psychology at the University of Maryland studying the psychosocial aspects of health under Dr. Mary Ann Hoffman. She is particularly interested in Celiac Disease as multiple women in her family struggle with the disease and its limitations.

To contact the researcher, email ejreeves@umd.edu.



LIVING WITH CELIAC DISEASE?

Help other women who are too.

How?	Requirements	Sign up!
<p>A 20-30 minute survey about your experience with Celiac.</p> <p>Answer questions about:</p> <ul style="list-style-type: none">• How its symptoms and restrictions may interfere with your life• How you cope with the challenges of the disease	<ul style="list-style-type: none">• Female• At least 18 years old• Diagnosed with Celiac Disease• Strictly adhere to Gluten Free diet	<p>If this sounds like you, visit [insert link here] or scan the code below.</p> <p>To contact the researcher, email ejreeves@umd.edu.</p>

About the researcher:

Elizabeth Reeves is a Doctoral student in Counseling Psychology at the University of Maryland studying the psychosocial aspects of health under Dr. Mary Ann Hoffman. She is particularly interested in Celiac Disease as multiple women in her family struggle with the disease and its limitations.

Survey Link: [insert link]
Contact: ejreeves@umd.edu

Survey Link: [insert link]
Contact: ejreeves@umd.edu

Survey Link: [insert link]
Contact: ejreeves@umd.edu

Survey Link: [insert link]
Contact: ejreeves@umd.edu

Survey Link: [insert link]
Contact: ejreeves@umd.edu

Survey Link: [insert link]
Contact: ejreeves@umd.edu

Survey Link: [insert link]
Contact: ejreeves@umd.edu

Survey Link: [insert link]
Contact: ejreeves@umd.edu

Informed Consent

<p>Purpose of the Study</p>	<p><i>This research is being conducted by Elizabeth Reeves and Mary Ann Hoffman at the University of Maryland, College Park. We are inviting you to participate in this research project because you are female, at least 18 years of age, are diagnosed with Celiac Disease and attempt to follow a strict gluten free diet. The purpose of this research project is to better understand the experience of women with Celiac. In particular, we are interested in understanding how women experience and cope with interpersonal stressors associated with the symptoms and/or strict gluten free diet.</i></p>
<p>Procedures</p>	<p><i>This is an online study that involves completing a survey about you, your experiences with Celiac Disease, and how it affects your interpersonal experiences and your life. In total, this study is anticipated to require 20-30 minutes of your time.</i></p>
<p>Potential Risks and Discomforts</p>	<p><i>There may be some risks from participating in this research study. You may have both positive and negative feelings about your health and how Celiac Disease affects your life, and this may induce feelings of discomfort or sadness. If for any reason you feel you need to contact the researchers, you can do so at ejreeves@umd.edu. There is also the risk of inadvertent disclosure if you do not complete the intervention in a private location and someone sees your responses.</i></p>
<p>Potential Benefits</p>	<p><i>There are no direct benefits to participation. However, possible benefits include feeling a better sense of understanding or improve well-being after reflecting on your experiences. We hope that, in the future, other people might benefit from this study through improved understanding of what can be helpful for women with Celiac Disease.</i></p>
<p>Confidentiality</p>	<p><i>The research team will minimize any potential loss of confidentiality by storing data in a locked office and password protected computer. Moreover, your identifying information will not be linked to your survey or written responses. Only members of the research team will have access to your responses. If we write a report or article about this research project, your identity will be protected to the maximum extent possible. Your information may be shared with representatives of the University of Maryland, College Park or governmental authorities if you or someone else is in danger or if we are required to do so by law.</i></p>
<p>Medical Treatment</p>	<p><i>The University of Maryland does not provide any medical, hospitalization or other insurance for participants in this research study, nor will the University of Maryland provide any medical treatment or compensation for any injury sustained as a result of participation in this research study,</i></p>

FEMINIST PERSPECTIVE CHRONIC DISEASE

	<i>except as required by law.</i>
Right to Withdraw and Questions	<p><i>Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time.</i></p> <p><i>If you decide to stop taking part in the study, if you have questions, concerns, or complaints, please contact the primary investigator, Elizabeth Reeves, at 3214 Benjamin Building, University of Maryland, College Park, MD 20742, ejreeves@umd.edu</i></p>
Participant Rights	<p><i>If you have questions about your rights as a research participant or wish to report a research-related injury, please contact:</i></p> <p style="text-align: center;">University of Maryland College Park Institutional Review Board Office 1204 Marie Mount College Park, Maryland, 20742 E-mail: irb@umd.edu Telephone: 301-405-0678</p> <p><i>This research has been reviewed according to the University of Maryland, College Park IRB procedures for research involving human subjects.</i></p>
Statement of Consent	<p><i>By clicking on the “next” button, this indicates that you are a woman of at least 18 years of age; you are able to read and write in English; you are diagnosed with Celiac Disease and attempt to follow a strict gluten free diet; you have read this consent form or have had it read to you; your questions have been answered to your satisfaction and you voluntarily agree to participate in this research study. You may print a copy of this consent form.</i></p> <p><i>If you agree to participate, please click “next”.</i></p>

FEMINIST PERSPECTIVE CHRONIC DISEASE

Appendix C

Eligibility Criteria and Demographics Questionnaire

Eligibility Criteria

Eligibility Criteria (*=does not meet eligibility)

- 1. Are you a woman of at least 18 years old? Yes __ No __*
- 2. Have you been officially diagnosed with Celiac Disease (by a licensed healthcare practitioner)? Yes __ No __*
- 3. How long after experiencing symptoms were you diagnosed? Please describe what the process of diagnosis was like for you.

- 4. Do you attempt to follow a completely gluten-free diet?
Always __ Often __ Sometimes __ Rarely __* Never __*
- 5. If you do not attempt to follow a gluten-free diet all of the time, please describe the circumstances when you do not adhere:

If participants are ineligible

Unfortunately you do not meet the eligibility criteria for this study. We appreciate your interest.

Demographics Questionnaire

Age: __

Racial/ethnic background (mark all that apply):

- African American/Black
- Asian-American/Pacific Islander
- Asian-Indian/Pakistani
- Biracial/Multiracial
- Hispanic/Latina
- Middle Eastern/Arab
- Native American/Native Alaskan
- White/European American
- Foreign National (please specify): _____
- Other (please specify): _____

Family's household income (before taxes):

- Less than 30,000
- 30,000-59,999,
- 60,000-99,999
- 100,000-149,999
- 150,000 or higher

FEMINIST PERSPECTIVE CHRONIC DISEASE

What is the highest level of education you have successfully completed?

- Less than high school
- High school
- 2-year college
- Technical school
- 4-year college
- Masters degree
- Doctorate

What is your employment status?

- Not employed
- Employed part-time
- Employed full-time
- Student

Relationship status:

- Single
- Unmarried, in a committed relationship
- Unmarried, living with partner
- Married, living with partner
- Separated
- Divorced
- Widowed

Do you currently live with family members or roommates who are also diagnosed with Celiac Disease?

Yes No

Who diagnosed you with Celiac Disease?

- Primary Care Provider (M.D.)
- Primary Care Provider (N.P. or P.A.)
- Specialist (e.g., Gastroenterologist, M.D.)
- Other (please specify): _____

Which medical tests were used to determine your diagnosis (select all that apply)?

- Blood test
- Intestinal biopsy
- Genetic test
- Symptoms
- Other (please specify): _____

Approximately how old were you when you were diagnosed?

___ years old

Approximately how long has it been since your diagnosis?

FEMINIST PERSPECTIVE CHRONIC DISEASE

___ years ___ months

Are you currently diagnosed with any additional autoimmune diseases (select all that apply)?

- Addison's Disease
- Autoimmune Thyroid Disease (Graves/Hashimoto's)
- Autoimmune Hepatitis
- Arthritis
- Colitis
- Crohn's Disease
- Dermatitis Herpetiformis
- Diabetes Type I
- Multiple Sclerosis
- Sjogren's Syndrome
- Other (please specify): _____

Are you currently diagnosed with any additional chronic health problems? Please list all that apply: _____

Please describe the most difficult Celiac Disease-related symptom(s) that you experience.

On a scale ranging from (1) very mild to (5) very severe, please indicate how severe these symptoms are.

1. very mild (2) mild (3) moderate (4) severe (5) very severe

On a scale ranging from (1) never to (5) always, please indicate how frequently these symptoms occur in a typical day.

(1) never (2) rarely (3) sometimes (4) often (5) always

Appendix D

Interpersonal Stress Survey

Please describe the most stressful interpersonal aspect of living with Celiac Disease that you have experienced in the past month. This might relate to the impact of disease restrictions or symptoms on family life, work life, or socializing with friends. It might include things like unwanted visibility and self-disclosure, feeling neglected or forgotten, or experiencing difficult emotions including isolation, shame and fear. Please describe the interpersonal stressor and explain how it affects you and your daily life.

On a scale ranging from (1) very mild to (5) very severe, please indicate the severity of this stressor in the past month.

1. very mild (2) mild (3) moderate (4) severe (5) very severe

On a scale ranging from (1) never to (5) always, please indicate how frequently this stressor occurred the past month.

(1) never (2) rarely (3) sometimes (4) often (5) always

Please describe the ways in which you coped with this interpersonal stressor in the past month. This might include a description of strategies or techniques that you used in response to the stress to manage difficult situations or help yourself feel better.

On a scale ranging from (1) not at all to (5) extremely, please indicate how helpful this coping strategy or technique was in managing the interpersonal stress this past month.

(1) not at all (2) slightly (3) somewhat (4) very (5) extremely

Appendix E

Emotional Approach Coping Scale (EAC)
Stanton, Kirk, Cameron & Danoff-Burg (2000)

We are interested in how people respond when they confront stressful interpersonal experiences as a result of their Celiac Disease. There are many ways to deal with this type of stress. We want to know to what extent (how much or how frequently) you have been doing what each of these items say. When recording your answers below, please think about, in the past month, your responses to the interpersonal stress you described above. Make your answers as true for you as you can.

Use the following scale to record your answers.

- 1 = I haven't been doing this at all
- 2 = I've been doing this a little bit
- 3 = I've been doing this a medium amount
- 4 = I've been doing this a lot

Emotional Processing

I take time to figure out what I'm really feeling.
I delve into my feelings to get a thorough understanding of them.
I realize that my feelings are valid and important.
I acknowledge my emotions.

Emotional Expression

I let my feelings come out freely.
I take time to express my emotions.
I allow myself to express my emotions.
I feel free to express my emotions.

Appendix F

Perceived Social Receptivity

(Stanton et al., 2000)

Please rate the degree to which you agree or disagree with the following statements on the scale below, in the past month:

- 1 = Strongly disagree
- 2 = Disagree
- 3 = Neither agree nor disagree
- 4 = Agree
- 5 = Strongly agree

1. I have people to talk to about my worries concerning Celiac Disease.
2. I feel free to express all my feelings about Celiac Disease to those close to me.
3. There are people I can count on whenever I want to talk about my experience with Celiac Disease.

Appendix G

The Silencing the Self Scale

Jack & Dill (1992)

Please circle the number that best describes how you feel about each of the statements listed below, in general. If you are not currently in an intimate relationship, please indicate how you felt and acted in your previous intimate relationships, or how you imagine you would act in intimate relationships based on your relationships with others.

- 1 = Strongly disagree
- 2 = Somewhat disagree
- 3 = Neither agree nor disagree
- 4 = Somewhat agree
- 5 = Strongly agree

1. I think it is best to put myself first because no one else will look out for me.
2. I don't speak my feelings in an intimate relationship when I know they will cause disagreement.
3. Caring means putting the other person's needs in front of my own.
4. Considering my needs to be as important as those of the people I love is selfish.
5. I find it is harder to be myself when I am in a close relationship than when I am on my own.
6. I tend to judge myself by how I think other people see me.
7. I feel dissatisfied with myself because I should be able to do all the things people are supposed to be able to do these days.
8. When my partner's needs and feelings conflict with my own, I always state mine clearly.
9. In a close relationship, my responsibility is to make the other person happy.
10. Caring means choosing to do what the other person wants, even when I want to do something different.
11. In order to feel good about myself, I need to feel independent and self-sufficient.
12. One of the worst things I can do is to be selfish.
13. I feel I have to act in a certain way to please my partner.
14. Instead of risking confrontations in close relationships, I would rather not rock the boat.
15. I speak my feelings with my partner, even when it leads to problems or disagreements.
16. Often I look happy enough on the outside, but inwardly I feel angry and rebellious.
17. In order for my partner to love me, I cannot reveal certain things about myself to him/her.
18. When my partner's needs or opinions conflict with mine, rather than asserting my own point of view I usually end up agreeing with him/her.
19. When I am in a close relationship I lose my sense of who I am.
20. When it looks as though certain of my needs can't be met in a relationship, I usually realize that they weren't very important anyway.

FEMINIST PERSPECTIVE CHRONIC DISEASE

21. My partner loves and appreciates me for who I am.
22. Doing things just for myself is selfish.
23. When I make decisions, other people's thoughts and opinions influence me more than my own thoughts and opinions.
24. I rarely express my anger at those close to me.
25. I feel that my partner does not know my real self.
26. I think it's better to keep my feelings to myself when they do conflict with my partner's.
27. I often feel responsible for other people's feelings.
28. I find it hard to know what I think and feel because I spend a lot of time thinking about how other people are feeling.
29. In a close relationship I don't usually care what we do, as long as the other person is happy.
30. I try to bury my feelings when I think they will cause trouble in my close relationship(s).
31. I never seem to measure up to the standards I set for myself.

Appendix H

Revised-Unmitigated Communion Scale

Fritz & Helgeson (1998)

Instructions: Using the scale below, place a number in the blank beside each statement that indicates the extent to which you agree or disagree, in general. Think of the people close to you – friends or family – in responding to each statement.

- 1 = Strongly disagree
- 2 = Slightly disagree
- 3 = Neither agree nor disagree
- 4 = Slightly agree
- 5 = Strongly agree

1. I *always* place the needs of others above my own.
2. I never find myself getting overly involved in others' problems.
3. For me to be happy, I need others to be happy.
4. I worry about how other people get along without me when I am not there.
5. I have *no* trouble getting to sleep at night when other people are upset.
6. It is impossible for me to satisfy my own needs when they interfere with the needs of others.
7. I can't say no when someone asks me for help.
8. Even when exhausted, I will always help other people.
9. I often worry about others' problems.

FEMINIST PERSPECTIVE CHRONIC DISEASE

Appendix I

Brief Symptom Inventory Derogatis (2000)

Below is a list of problems people sometimes have. Read each one carefully and fill in the circle that best describes HOW MUCH THAT PROBLEM HAS DISTRESSED OR BOTHERED YOU DURING THE PAST 7 DAYS INCLUDING TODAY.

- 0 = Not at All
- 1 = A little Bit
- 2 = Moderately
- 3 = Quite a Bit
- 4 = Extremely

Example items include:

- 1. Faintness or dizziness
- 5. Feeling lonely
- 9. Suddenly scared for no reason
- 14. Feeling hopeless about the future

Note: The entire measure is not shown because the BSI® is a registered trademark of Leonard R. Derogatis, Ph. D. Handouts with all items will be provided at the committee proposal meeting.

Appendix J

Celiac Disease-Quality of Life Scale

Dorn, Hernandez, Minayas, Morris, Leseran, Lewis, Lee, Bangdiwala, Greens & Drossman (2009)

Please think about your life over the past month (30 days), and look at the statements below. Each statement has five possible responses. For each statement, please select the response that best describes your feelings.

- 1 = Not at all
- 2 = Slightly
- 3 = Moderately
- 4 = Quite a bit
- 5 = A great deal

1. I feel limited by this disease.
2. I feel worried that I will suffer from this disease.
3. I feel concerned that this disease will cause other health problems.
4. I feel worried about my increased risk of cancer from this disease.
5. I feel socially stigmatized for having this disease.
6. I feel like I'm limited in eating meals with coworkers.
7. I feel like I am not able to have special foods like birthday cake and pizza.
8. I feel that the diet is sufficient treatment for my disease.
9. I feel that there are not enough choices for treatment.
10. I feel depressed because of my disease.
11. I feel frightened by having this disease.
12. I feel like I don't know enough about the disease.
13. I feel overwhelmed about having this disease
14. I have trouble socializing because of my disease.
15. I find it difficult to travel or take long trips because of my disease.
16. I feel like I cannot live a normal life because of my disease.
17. I feel afraid to eat out because my food may be contaminated.
18. I feel worried about the increased risk of one of my family members having Celiac Disease.
19. I feel like I think about food all time.
20. I feel concerned that my long-term health will be affected.

References

- Ali, A., Oatley, K., & Toner, B. B. (2002). Life Stress, Self-silencing, and Domains of Meaning in Unipolar Depression: an Investigation of an Outpatient Sample of Women. *Journal of Social and Clinical Psychology, 21*(6), 669–685.
<https://doi.org/10.1521/jscp.21.6.669.22797>
- Amirkhan, J. H., Risinger, R. T., & Swickert, R. J. (1995). Extraversion: A “Hidden” Personality Factor in Coping? *Journal of Personality, 63*(2), 189–212.
<https://doi.org/10.1111/1467-6494.ep9506231774>
- Austenfeld, J. L., & Stanton, A. L. (2004). Coping Through Emotional Approach: A New Look at Emotion, Coping, and Health-Related Outcomes. *Journal of Personality, 72*(6), 1335–1364. <https://doi.org/10.1111/j.1467-6494.2004.00299.x>
- Ball, K., & Kenardy, J. (2002). Body weight, body image, and eating behaviours: Relationships with ethnicity and acculturation in a community sample of young Australian women. *Eating Behaviors, 3*(3), 205–216.
[https://doi.org/10.1016/S1471-0153\(02\)00062-4](https://doi.org/10.1016/S1471-0153(02)00062-4)
- Batenburg, A., & Das, E. (2014). Emotional Approach Coping and the Effects of Online Peer-Led Support Group Participation Among Patients With Breast Cancer: A Longitudinal Study. *Journal of Medical Internet Research, 16*(11).
<https://doi.org/10.2196/jmir.3517>
- Bem, S. L. (1974). The measurement of psychological androgyny. *Journal of Consulting and Clinical Psychology, 42*, 155–162.
- Berghuis, J. P., & Stanton, A. L. (2002). Adjustment to a dyadic stressor: A longitudinal study of coping and depressive symptoms in infertile couples over an

FEMINIST PERSPECTIVE CHRONIC DISEASE

insemination attempt. *Journal of Consulting and Clinical Psychology*, 70(2), 433–438. <https://doi.org/10.1037/0022-006X.70.2.433>

Besser, A., Flett, G. L., & Davis, R. A. (2003). Self-criticism, dependency, silencing the self, and loneliness: a test of a mediational model. *Personality and Individual Differences*, 35(8), 1735–1752. [https://doi.org/10.1016/S0191-8869\(02\)00403-8](https://doi.org/10.1016/S0191-8869(02)00403-8)

Black, J. L., & Orfila, C. (2011). Impact of coeliac disease on dietary habits and quality of life. *Journal of Human Nutrition and Dietetics*, 24(6), 582–587. <https://doi.org/10.1111/j.1365-277X.2011.01170.x>

Boyes, M. E., & French, D. J. (2009). Having a Cyberball: Using a ball-throwing game as an experimental social stressor to examine the relationship between neuroticism and coping. *Personality and Individual Differences*, 47(5), 396–401. <https://doi.org/10.1016/j.paid.2009.04.005>

Brody, L. R. (1999). *Gender, Emotion and the Family*. Cambridge, MA: Harvard University Press.

Brody, L. R., Stokes, L. R., Dale, S. K., Kelso, G. A., Cruise, R. C., Weber, K. M., ... Cohen, M. H. (2014). Gender Roles and Mental Health in Women With and at Risk for HIV. *Psychology of Women Quarterly*, 38(3), 311–326. <https://doi.org/10.1177/0361684314525579>

Brody, L. R., Stokes, L. R., Kelso, G. A., Dale, S. K., Cruise, R. C., Weber, K. M., ... Cohen, M. H. (2014a). Gender Role Behaviors of High Affiliation and Low Self-Silencing Predict Better Adherence to Antiretroviral Therapy in Women with HIV. *AIDS Patient Care and STDs*, 28(9), 459–461. <https://doi.org/10.1089/apc.2014.0068>

FEMINIST PERSPECTIVE CHRONIC DISEASE

Brody, L. R., Stokes, L. R., Kelso, G. A., Dale, S. K., Cruise, R. C., Weber, K. M., ...

Cohen, M. H. (2014b). Gender Role Behaviors of High Affiliation and Low Self-Silencing Predict Better Adherence to Antiretroviral Therapy in Women with HIV. *AIDS Patient Care and STDs*, 28(9), 459–461.

<https://doi.org/10.1089/apc.2014.0068>

Calam, R., Waller, G., Slade, P., & Newton, T. (1990). Eating Disorders and Perceived Relationships with Parents. *International Journal of Eating Disorders*, 9(5), 479–485.

Carr, J. G., & Gilroy, F. D. (1996). Silencing the Self and Depression Among Women. *Psychology of Women Quarterly*, 20(3), 375.

Celiac Disease and Autoimmunity: Review and Controversies - Springer. (n.d.).

<https://doi.org/10.1007/s11882-013-0352-1>

Chapman, D. P., Perry, G. S., & Strine, T. W. (2004). The Vital Link Between Chronic Disease and Depressive Disorders. *Preventing Chronic Disease*, 2(1). Retrieved from <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1323317/>

Choi, J. M., Lebwohl, B., Wang, J., Lee, S. K., Murray, J. A., Sauer, M. V., & Green, P. H. R. (2011). Increased Prevalence of Celiac Disease in Patients with Unexplained Infertility in the United States: A Prospective Study. *The Journal of Reproductive Medicine*, 56(5-6), 199–203.

Ciaramella, A., & Poli, P. (2001). Assessment of depression among cancer patients: the role of pain, cancer type and treatment. *Psycho-Oncology*, 10(2), 156–165.

<https://doi.org/10.1002/pon.505>

FEMINIST PERSPECTIVE CHRONIC DISEASE

- Connor-Smith, J. K., & Compas, B. E. (2002). Vulnerability to Social Stress: Coping as a Mediator or Moderator of Sociotropy and Symptoms of Anxiety and Depression. *Cognitive Therapy and Research*, 26(1), 39–55.
<https://doi.org/10.1023/A:1013889504101>
- Connor-Smith, J. K., & Compas, B. E. (2004). Coping as a Moderator of Relations Between Reactivity to Interpersonal Stress, Health Status, and Internalizing Problems. *Cognitive Therapy and Research*, 28(3), 347–368.
<https://doi.org/10.1023/B:COTR.0000031806.25021.d5>
- Cramer, K. M., Gallant, M. D., & Langlois, M. W. (2005). Self-silencing and depression in women and men: Comparative structural equation models. *Personality and Individual Differences*, 39(3), 581–592.
<https://doi.org/10.1016/j.paid.2005.02.012>
- Cramer, K. M., & Thoms, N. (2003). Factor structure of the silencing the self scale in women and men. *Personality and Individual Differences*, 35(3), 525–535.
[https://doi.org/10.1016/S0191-8869\(02\)00216-7](https://doi.org/10.1016/S0191-8869(02)00216-7)
- Danoff-Burg, S., Mosher, C. E., & Grant, C. A. (2006). Relations of agentic and communal personality traits to health behavior and substance use among college students. *Personality and Individual Differences*, 40(2), 353–363.
<https://doi.org/10.1016/j.paid.2005.05.020>
- Danoff-Burg, S., Tracey A. Trudeau, Kimberlee J. Paget, Stephen A. (2004). Unmitigated Communion, Social Constraints, and Psychological Distress Among Women With Rheumatoid Arthritis. *Journal of Personality*, 72(1), 29–46.
<https://doi.org/10.1111/j.0022-3506.2004.00255.x>

FEMINIST PERSPECTIVE CHRONIC DISEASE

- Delormier, T., Frohlich, K. L., & Potvin, L. (2009). Food and eating as social practice – understanding eating patterns as social phenomena and implications for public health. *Sociology of Health & Illness*, 31(2), 215–228.
<https://doi.org/10.1111/j.1467-9566.2008.01128.x>
- Denham, J. M., & Hill, I. D. (2013). Celiac Disease and Autoimmunity: Review and Controversies. *Current Allergy and Asthma Reports*, 13(4), 347–353.
<https://doi.org/10.1007/s11882-013-0352-1>
- Denton, M., Prus, S., & Walters, V. (2004). Gender differences in health: a Canadian study of the psychosocial, structural and behavioural determinants of health. *Social Science & Medicine*, 58(12), 2585–2600.
<https://doi.org/10.1016/j.socscimed.2003.09.008>
- Derogatis, L. R., Rickels, K., & Rock, A. F. (1976). The SCL-90 and the MMPI: a step in the validation of a new self-report scale. *The British Journal of Psychiatry*, 128(3), 280–289. <https://doi.org/10.1192/bjp.128.3.280>
- Dickens, Chris, Linda, M., Clark-Carter, D., & Creed, F. (2002). Depression in Rheumatoid Arthritis: A Systematic Review of the Literature With Meta-Analysis. *Psychosomatic Medicine*, 64, 52–60.
- Dorn, S. D., Hernandez, L., Minaya, M. T., Morris, C. B., Hu, Y., Leserman, J., ... Drossman, D. A. (2010). The development and validation of a new coeliac disease quality of life survey (CD-QOL). *Alimentary Pharmacology & Therapeutics*, 31(6), 666–675. <https://doi.org/10.1111/j.1365-2036.2009.04220.x>
- Dorn, S. D., Hernandez, L., Minaya, M. T., Morris, C. B., Hu, Y., Lewis, S., ... Drossman, D. A. (2010). Psychosocial Factors Are More Important Than Disease

FEMINIST PERSPECTIVE CHRONIC DISEASE

Activity in Determining Gastrointestinal Symptoms and Health Status in Adults at a Celiac Disease Referral Center. *Digestive Diseases and Sciences*, 55(11), 3154–3163. <https://doi.org/10.1007/s10620-010-1342-y>

Eagly, A. H. (1987). *Sex differences in social behavior: A social role interpretation*. Hillsdale, NJ: Erlbaum.

Eagly, A. H., & Steffen, V. J. (1984). Gender stereotypes stem from the distribution of women and men into social roles. *Journal of Personality and Social Psychology*, 46(4), 735–754. <https://doi.org/10.1037/0022-3514.46.4.735>

Fasano, A., & Catassi, C. (2012). Celiac Disease. *New England Journal of Medicine*, 367(25), 2419–2426. <https://doi.org/10.1056/NEJMcp1113994>

Folkman, S. (2010). *The Oxford Handbook of Stress, Health, and Coping*. Oxford University Press, USA.

Frank, J. B., & Thomas, C. D. (2003). Externalized self-perceptions, self-silencing, and the prediction of eating pathology. *Canadian Journal of Behavioural Science/Revue Canadienne Des Sciences Du Comportement*, 35(3), 219–228. <https://doi.org/10.1037/h0087203>

Fritz, H. L. (2000). Gender-linked personality traits predict mental health and functional status following a first coronary event. *Health Psychology*, 19(5), 420–428. <https://doi.org/10.1037/0278-6133.19.5.420>

Fritz, H. L., & Helgeson, V. S. (1998). Distinctions of unmitigated communion from communion: Self-neglect and overinvolvement with others. *Journal of Personality and Social Psychology*, 75(1), 121–140. <https://doi.org/10.1037/0022-3514.75.1.121>

FEMINIST PERSPECTIVE CHRONIC DISEASE

- Fritz, M. S., & MacKinnon, D. P. (2007). Required Sample Size to Detect the Mediated Effect. *Psychological Science, 18*(3), 233–239.
- Geller, J., Cockell, S. J., Hewitt, P. L., Goldner, E. M., & Flett, G. L. (2000). Inhibited expression of negative emotions and interpersonal orientation in anorexia nervosa. *International Journal of Eating Disorders, 28*(1), 8–19.
[https://doi.org/10.1002/1098-108X\(200007\)28:1<8::AID-EAT2>3.0.CO;2-U](https://doi.org/10.1002/1098-108X(200007)28:1<8::AID-EAT2>3.0.CO;2-U)
- Hallert, C., Grännö, C., Grant, C., Hultén, S., Midhagen, G., Ström, M., ... Wickström, T. (1998). Quality of Life of Adult Coeliac Patients Treated for 10 Years. *Scandinavian Journal of Gastroenterology, 33*(9), 933–938.
<https://doi.org/10.1080/003655298750026949>
- Hallert, C., Grännö, C., Hultén, S., Midhagen, G., Ström, M., Svensson, H., & Valdimarsson, T. (2002). Living with Coeliac Disease: Controlled Study of the Burden of Illness. *Scandinavian Journal of Gastroenterology, 37*(1), 39–42.
<https://doi.org/10.1080/003655202753387338>
- Hallert, C., Sandlund, O., & Broqvist, M. (2003). Perceptions of health-related quality of life of men and women living with coeliac disease. *Scandinavian Journal of Caring Sciences, 17*(3), 301–307. <https://doi.org/10.1046/j.1471-6712.2003.00228.x>
- Harbo, H. F., Gold, R., & Tintoré, M. (2013). Sex and gender issues in multiple sclerosis. *Therapeutic Advances in Neurological Disorders, 6*(4), 237–248.
<https://doi.org/10.1177/1756285613488434>
- Helgeson, V. S. F., Heidi L. (1998). A Theory of Unmitigated Communion. *Personality & Social Psychology Review (Lawrence Erlbaum Associates), 2*(3), 173.

FEMINIST PERSPECTIVE CHRONIC DISEASE

Helgeson, V. (2010). Gender, Stress and Coping. In S. Folkman (Ed.), *The Oxford Handbook of Stress, Health and Coping* (pp. 63–85). Oxford University Press.

Helgeson, V., & Fritz, H. L. (1996). Implications of unmitigated communion and communion for adolescent adjustment to Type I diabetes. *Women's Health: Research on Gender, Behavior, and Policy*, 2, 163–188.

Helgeson, V. S. (1993). Implications of agency and communion for patient and spouse adjustment to a first coronary event. *Journal of Personality and Social Psychology*, 64(5), 807–816. <https://doi.org/10.1037/0022-3514.64.5.807>

Helgeson, V. S. (1994). Relation of agency and communion to well-being: Evidence and potential explanations. *Psychological Bulletin*, 116(3), 412–428. <https://doi.org/10.1037/0033-2909.116.3.412>

Helgeson, V. S. (2003). Unmitigated Communion and Adjustment to Breast Cancer: Associations and Explanations¹. *Journal of Applied Social Psychology*, 33(8), 1643–1661. <https://doi.org/10.1111/j.1559-1816.2003.tb01967.x>

Helgeson, V. S. (2008). Gender-Related Traits and Health. In J. Suls & K. A. Wallston (Eds.), *Social Psychological Foundations of Health and Illness*. John Wiley & Sons.

Helgeson, V. S., & Fritz, H. L. (1999). Unmitigated Agency and Unmitigated Communion: Distinctions from Agency and Communion. *Journal of Research in Personality*, 33(2), 131–158. <https://doi.org/10.1006/jrpe.1999.2241>

Helgeson, V. S., & Fritz, H. L. (2000). The Implications of Unmitigated Agency and Unmitigated Communion for Domains of Problem Behavior. *Journal of Personality*, 68(6), 1031–1057. <https://doi.org/10.1111/1467-6494.00125>

FEMINIST PERSPECTIVE CHRONIC DISEASE

- Helgeson, V. S., & Palladino, D. K. (2012). Agentic and Communal Traits and Health Adolescents With and Without Diabetes. *Personality and Social Psychology Bulletin*, 38(4), 415–428. <https://doi.org/10.1177/0146167211427149>
- Hooker, K., Frazier, L. D., & Monahan, D. J. (1994). Personality and Coping Among Caregivers of Spouses With Dementia. *The Gerontologist*, 34(3), 386–392. <https://doi.org/10.1093/geront/34.3.386>
- Hyde, J. S. (2005). The Gender Similarities Hypothesis. *American Psychologist*, 60(6), 581–592. <https://doi.org/10.1037/0003-066X.60.6.581>
- Jack, D. C. (1991). *Silencing the self: Women and depression* (Vol. viii). Cambridge, MA, US: Harvard University Press.
- Jack, D. C. (2011). Reflections on the Silencing the Self Scale and Its Origins. *Psychology of Women Quarterly*, 35(3), 523–529. <https://doi.org/10.1177/0361684311414824>
- Jackson, D. c., & Dillon, D. (1992). The Silencing the Self Scale. *Psychology of Women Quarterly*, 16(1), 97.
- Jordan, J. V. (2001). A relational-cultural model: Healing through mutual empathy. *Bulletin of the Menninger Clinic*, 65(1), 92.
- Jordan, J. V., Kaplan, A. G., Miller, J., Stiver, I. P., & Surrey, J. L. (1991). *Women's growth in connection: Writings from the Stone Center*. New York, NY: Guildford Press.
- Katz, M. R., Irish, J. C., Devins, G. M., Rodin, G. M., & Gullane, P. J. (2003). Psychosocial adjustment in head and neck cancer: The impact of disfigurement,

FEMINIST PERSPECTIVE CHRONIC DISEASE

gender and social support. *Head & Neck*, 25(2), 103–112.

<https://doi.org/10.1002/hed.10174>

Katz, P. P., & Criswell, L. A. (1996). Differences in symptom reports between men and women with rheumatoid arthritis. *Arthritis & Rheumatism*, 9(6), 441–448.

<https://doi.org/10.1002/art.1790090605>

Kayser, K., Sormanti, M., & Strainchamps, E. (1999). Women Coping with Cancer The Influence of Relationship Factors on Psychosocial Adjustment. *Psychology of Women Quarterly*, 23(4), 725–739. [https://doi.org/10.1111/j.1471-](https://doi.org/10.1111/j.1471-6402.1999.tb00394.x)

[6402.1999.tb00394.x](https://doi.org/10.1111/j.1471-6402.1999.tb00394.x)

Keller, M., & Henrich, G. (1999). Illness-related Distress: Does it Mean the Same for Men and Women?: Gender Aspects in Cancer Patients' Distress and Adjustment. *Acta Oncologica*, 38(6), 747–755.

Kiecolt-Glaser JK, Loving TJ, Stowell JR, & et al. (2005). HOstile marital interactions, proinflammatory cytokine production, and wound healing. *Archives of General Psychiatry*, 62(12), 1377–1384. <https://doi.org/10.1001/archpsyc.62.12.1377>

Kralik, D. (2002). The quest for ordinariness: transition experienced by midlife women living with chronic illness. *Journal of Advanced Nursing*, 39(2), 146–154.

<https://doi.org/10.1046/j.1365-2648.2000.02254.x>

Kvien, T. K., Uhlig, T., Ødegård, S., & Heiberg, M. S. (2006). Epidemiological aspects of rheumatoid arthritis: the sex ratio. *Annals of the New York Academy of Sciences*, 1069, 212–222. <https://doi.org/10.1196/annals.1351.019>

FEMINIST PERSPECTIVE CHRONIC DISEASE

- Lee, A. R., Ng, D. L., Diamond, B., Ciaccio, E. J., & Green, P. H. R. (2012). Living with coeliac disease: survey results from the USA. *Journal of Human Nutrition and Dietetics*, 25(3), 233–238. <https://doi.org/10.1111/j.1365-277X.2012.01236.x>
- Liang, B., Tracy, A., Taylor, C. A., Williams, L. M., Jordan, J. V., & Miller, J. B. (2002). The Relational Health Indices: A Study of Women's Relationships. *Psychology of Women Quarterly*, 26(1), 25.
- Lieberman, M., Gauvin, L., Bukowski, W. M., & White, D. R. (2001). Interpersonal influence and disordered eating behaviors in adolescent girls: The role of peer modeling, social reinforcement, and body-related teasing. *Eating Behaviors*, 2(3), 215–236. [https://doi.org/10.1016/S1471-0153\(01\)00030-7](https://doi.org/10.1016/S1471-0153(01)00030-7)
- Lorenzo, C. M. de, Xikota, J. C., Wayhs, M. C., Nassar, S. M., & Pires, M. M. de S. (2011). Evaluation of the quality of life of children with celiac disease and their parents: a case–control study. *Quality of Life Research*, 21(1), 77–85. <https://doi.org/10.1007/s11136-011-9930-7>
- Ludvigsson, J. F., Rubio-Tapia, A., van Dyke, C. T., Melton, L. J., Zinsmeister, A. R., Lahr, B. D., & Murray, J. A. (2013). Increasing Incidence of Celiac Disease in a North American Population. *The American Journal of Gastroenterology*, 108(5), 818–824. <https://doi.org/10.1038/ajg.2013.60>
- Megiorni, F., Mora, B., Bonamico, M., Barbato, M., Montuori, M., Viola, F., ... Mazzilli, M. C. (2008). HLA-DQ and Susceptibility to Celiac Disease: Evidence for Gender Differences and Parent-of-Origin Effects. *The American Journal of Gastroenterology*, 103(4), 997–1003. <https://doi.org/10.1111/j.1572-0241.2007.01716.x>

FEMINIST PERSPECTIVE CHRONIC DISEASE

- Merikangas KR, Ames M, Cui L, & et al. (2007). The impact of comorbidity of mental and physical conditions on role disability in the us adult household population. *Archives of General Psychiatry*, 64(10), 1180–1188.
<https://doi.org/10.1001/archpsyc.64.10.1180>
- Midhagen, G., & Hallert, C. (2003). High rate of gastrointestinal symptoms in celiac patients living on a gluten-free diet: controlled study. *The American Journal of Gastroenterology*, 98(9), 2023–2026. <https://doi.org/10.1111/j.1572-0241.2003.07632.x>
- Miller, G., Rohleder, N., & Cole, S. W. (2009). Chronic Interpersonal Stress Predicts Activation of Pro- and Anti- Inflammatory Signaling Pathways Six Months Later. *Psychosomatic Medicine*, 71(1), 57–62.
<https://doi.org/10.1097/PSY.0b013e318190d7de>
- Miller, J. B., & Stiver, I. P. (1997). *The healing connection: How women form relationships in therapy and in life* (Vol. xi). Boston, MA, US: Beacon Press.
- Miller, J., & Stiver, I. (1997). *The healing connection: How women form relationships in therapy and in life*. Boston, MA: Beacon Press.
- Morrison, T. G., & Sheahan, E. E. (2009). Gender-Related Discourses as Mediators in the Association Between Internalization of the Thin-Body Ideal and Indicators of Body Dissatisfaction and Disordered Eating. *Psychology of Women Quarterly*, 33(4), 374–383. <https://doi.org/10.1111/j.1471-6402.2009.01515.x>
- Nagurney, A. J. (2007). The effects of relationship stress and unmitigated communion on physical and mental health outcomes. *Stress and Health*, 23(4), 267–273.
<https://doi.org/10.1002/smi.1146>

FEMINIST PERSPECTIVE CHRONIC DISEASE

- Nagurney, A. J. (2008). The Effects of Unmitigated Communion and Life Events among Women with Fibromyalgia Syndrome. *Journal of Health Psychology, 13*(4), 520–528. <https://doi.org/10.1177/1359105308088523>
- NEUMARK-SZTAINER, D., STORY, M., PERRY, C., & CASEY, M. A. (1999). Factors Influencing Food Choices of Adolescents: Findings from Focus-Group Discussions with Adolescents. *Journal of the American Dietetic Association, 99*(8), 929–937. [https://doi.org/10.1016/S0002-8223\(99\)00222-9](https://doi.org/10.1016/S0002-8223(99)00222-9)
- O'Brien, T. B., & DeLongis, A. (1996). The Interactional Context of Problem-, Emotion-, and Relationship-Focused Coping: The Role of the Big Five Personality Factors. *Journal of Personality, 64*(4), 775–813. <https://doi.org/10.1111/1467-6494.ep9706272187>
- Orth-Gomér K, Wamala SP, Horsten M, Schenck-Gustafsson K, Schneiderman N, & Mittleman MA. (2000). Marital stress worsens prognosis in women with coronary heart disease: The stockholm female coronary risk study. *JAMA, 284*(23), 3008–3014. <https://doi.org/10.1001/jama.284.23.3008>
- Piran, N., & Cormier, H. C. (2005). The Social Construction of Women and Disordered Eating Patterns. *Journal of Counseling Psychology, 52*(4), 549–558. <https://doi.org/10.1037/0022-0167.52.4.549>
- Reilly, N. R., & Green, P. H. R. (2012). Epidemiology and clinical presentations of celiac disease. *Seminars in Immunopathology, 34*(4), 473–478. <https://doi.org/http://dx.doi.org/10.1007/s00281-012-0311-2>
- Reynolds, K. A., Helgeson, V. S., Seltman, H., Janicki, D., Page-Gould, E., & Wardle, M. (2006). Impact of Interpersonal Conflict on Individuals High in Unmitigated

FEMINIST PERSPECTIVE CHRONIC DISEASE

Communion1. *Journal of Applied Social Psychology*, 36(7), 1595–1616.

<https://doi.org/10.1111/j.0021-9029.2006.00146.x>

Reynolds, P., Hurley, S., Torres, M., Jackson, J., Boyd, P., & Chen, V. W. (2000). Use of Coping Strategies and Breast Cancer Survival: Results from the Black/White Cancer Survival Study. *American Journal of Epidemiology*, 152(10), 940–949.
<https://doi.org/10.1093/aje/152.10.940>

Roos, S., Kärner, A., & Hallert, C. (2006). Psychological well-being of adult coeliac patients treated for 10 years. *Digestive and Liver Disease*, 38(3), 177–180.
<https://doi.org/10.1016/j.dld.2006.01.004>

Rosario, M., Shinn, M., Mørch, H., & Huckabee, C. B. (1988). Gender Differences in Coping and Social Supports: Testing Socialization and Role Constraint Theories. *Journal of Community Psychology*, 16(1), 55–69.

Rubio-Tapia, A., Ludvigsson, J. F., Brantner, T. L., Murray, J. A., & Everhart, J. E. (2012). The Prevalence of Celiac Disease in the United States. *The American Journal of Gastroenterology*, 107(10), 1538–1544.
<https://doi.org/10.1038/ajg.2012.219>

Schupak-Neuberg, E., & Nemeroff, C. J. (1993). Disturbances in Identity and Self-Regulation in Bulimia Nervosa: Implications for a Metaphorical Perspective of “Body as Self.” *International Journal of Eating Disorders*, 13(4), 335–347.

Simrén, M., Abrahamsson, H., Svedlund, J., & Björnsson, E. S. (2001). Quality of Life in Patients with Irritable Bowel Syndrome Seen in Referral Centers Versus Primary Care: The Impact of Gender and Predominant Bowel Pattern. *Scandinavian*

FEMINIST PERSPECTIVE CHRONIC DISEASE

Journal of Gastroenterology, 36(5), 545–552.

<https://doi.org/10.1080/003655201750153476>

Smith, B. W., & Zautra, A. J. (2002). The role of personality in exposure and reactivity to interpersonal stress in relation to arthritis disease activity and negative affect in women. *Health Psychology*, 21(1), 81–88. <https://doi.org/10.1037/0278-6133.21.1.81>

Smith, D. F., & Gerdes, L. U. (2012). Meta-analysis on anxiety and depression in adult celiac disease. *Acta Psychiatrica Scandinavica*, 125(3), 189–193. <https://doi.org/10.1111/j.1600-0447.2011.01795.x>

Smith, J. A., Lumley, M. A., & Longo, D. J. (2002). Contrasting emotional approach coping with passive coping for chronic myofascial pain. *Annals of Behavioral Medicine*, 24(4), 326–35. https://doi.org/http://dx.doi.org/10.1207/S15324796ABM2404_09

Spence, J. (1984). Gender identity and its implications for the concepts of masculinity and femininity. *Current Theory and Research in Motivation*, 32, 59–95.

Spence, J. T. (1984). Gender identity and its implications for the concepts of masculinity and femininity. *Nebraska Symposium on Motivation*, 32, 59–95.

Spence, J. T., & Helmreich, R. L. (2014). *Masculinity and Femininity: Their Psychological Dimensions, Correlates, and Antecedents*. University of Texas Press.

Spence, J. T., Helmreich, R. L., & Stapp, J. (1974). The Personal Attributes Questionnaire: A measure of sex role stereotypes and masculinity-femininity.

FEMINIST PERSPECTIVE CHRONIC DISEASE

- Stanton, A. L., Collins, C. A., & Sworowski, L. A. (2001). Adjustment to chronic illness: Theory and research. In *Handbook of health psychology* (pp. 387–403).
- Stanton, A. L., Danoff-Burg, S., Cameron, C. L., Bishop, M., Collins, C. A., Kirk, S. B., ... Twillman, R. (2000). Emotionally expressive coping predicts psychological and physical adjustment to breast cancer. *Journal of Consulting and Clinical Psychology, 68*(5), 875–882. <https://doi.org/10.1037/0022-006X.68.5.875>
- Stanton, A. L., Kirk, S. B., Cameron, C. L., & Danoff-Burg, S. (2000a). Coping through emotional approach: Scale construction and validation. *Journal of Personality and Social Psychology, 78*(6), 1150–1169. <https://doi.org/10.1037/0022-3514.78.6.1150>
- Stanton, A. L., Kirk, S. B., Cameron, C. L., & Danoff-Burg, S. (2000b). Coping through emotional approach: Scale construction and validation. *Journal of Personality and Social Psychology, 78*(6), 1150–1169. <https://doi.org/10.1037/0022-3514.78.6.1150>
- Stanton, A. L., & Low, C. A. (2012). Expressing Emotions in Stressful Contexts Benefits, Moderators, and Mechanisms. *Current Directions in Psychological Science, 21*(2), 124–128. <https://doi.org/10.1177/0963721411434978>
- Stanton, A. L., Revenson, T. A., & Tennen, H. (2007). Health Psychology: Psychological Adjustment to Chronic Disease. *Annual Review of Psychology, 58*(1), 565–592. <https://doi.org/10.1146/annurev.psych.58.110405.085615>
- Sverker, A., Hensing, G., & Hallert, C. (2005). “Controlled by food” – lived experiences of coeliac disease. *Journal of Human Nutrition and Dietetics, 18*(3), 171–180. <https://doi.org/10.1111/j.1365-277X.2005.00591.x>

FEMINIST PERSPECTIVE CHRONIC DISEASE

- Sverker, A., Östlund, G., Hallert, C., & Hensing, G. (2009). "I lose all these hours..."—exploring gender and consequences of dilemmas experienced in everyday life with coeliac disease. *Scandinavian Journal of Caring Sciences*, 23(2), 342–352. <https://doi.org/10.1111/j.1471-6712.2008.00628.x>
- Tamres, L. K. J., Denise Helgeson, Vicki S. (2002). Sex Differences in Coping Behavior: A Meta-Analytic Review and an Examination of Relative Coping. *Personality & Social Psychology Review (Lawrence Erlbaum Associates)*, 6(1), 2–30.
- Tamres, L. K., Janicki, D., & Helgeson, V. S. (2002). Sex Differences in Coping Behavior: A Meta-Analytic Review and an Examination of Relative Coping. *Personality and Social Psychology Review*, 6(1), 2–30. https://doi.org/10.1207/S15327957PSPR0601_1
- Tantillo, M., & Sanftner, J. (2010). Measuring perceived mutuality in women with eating disorders: the development of the Connection-Disconnection Scale. *Journal of Nursing Measurement*, 18(2), 100–119. <https://doi.org/10.1891/1061-3749.18.2.100>
- Terry, D. J. (1994). Determinants of coping: The role of stable and situational factors. *Journal of Personality and Social Psychology*, 66(5), 895–910. <https://doi.org/10.1037/0022-3514.66.5.895>
- Troxel WM, Matthews KA, Gallo LC, & Kuller LH. (2005). Marital quality and occurrence of the metabolic syndrome in women. *Archives of Internal Medicine*, 165(9), 1022–1027. <https://doi.org/10.1001/archinte.165.9.1022>
- Trudeau, K. J., Dannoff-Burg, S., Revenson, T. A., & Paget, S. A. (2003). Agency and Communion in People With Rheumatoid Arthritis. *Sex Roles*, 49(7/8), 303–311.

FEMINIST PERSPECTIVE CHRONIC DISEASE

- Ward, B. W., Schiller, J. S., & Goodman, R. A. (2014). Multiple Chronic Conditions Among US Adults: A 2012 Update. *Preventing Chronic Disease, 11*.
<https://doi.org/10.5888/pcd11.130389>
- West, T. V., Heilman, M. E., Gullett, L., Moss-Racusin, C. A., & Magee, J. C. (2012). Building blocks of bias: Gender composition predicts male and female group members' evaluations of each other and the group. *Journal of Experimental Social Psychology, 48*(5), 1209–1212. <https://doi.org/10.1016/j.jesp.2012.04.012>
- Yunus, M. B. (2002). Gender differences in fibromyalgia and other related syndromes. *The Journal of Gender-Specific Medicine: JGSM: The Official Journal of the Partnership for Women's Health at Columbia, 5*(2), 42–47.
- Zarkadas, M., Cranney, A., Case, S., Molloy, M., Switzer, C., Graham, I., ... Burrows, V. (2006). The impact of a gluten-free diet on adults with coeliac disease: results of a national survey. *Journal of Human Nutrition & Dietetics, 19*(1), 41–49.
- Zarkadas, M., Dubois, S., Macisaac, K., Cantin, I., Rashid, M., Roberts, K. C., ... Pulido, O. M. (2013). Living with coeliac disease and a gluten-free diet: a Canadian perspective. *Journal of Human Nutrition & Dietetics, 26*(1), 10–23.
- Zautra, A. J., Hoffman, J., Potter, P., Matt, K. S., Yocum, D., & Castro, L. (1997). Examination of changes in interpersonal stress as a factor in disease exacerbations among women with rheumatoid arthritis. *Annals of Behavioral Medicine, 19*(3), 279–86. <https://doi.org/http://dx.doi.org/10.1007/BF02892292>
- Zingone, F., Iavarone, A., Tortora, R., Imperatore, N., Pellegrini, L., Russo, T., ... Ciacci, C. (2013). The Italian translation of the Celiac Disease-specific Quality of Life

FEMINIST PERSPECTIVE CHRONIC DISEASE

Scale in celiac patients on gluten free diet. *Digestive and Liver Disease*, 45(2),
115–118. <https://doi.org/10.1016/j.dld.2012.10.018>