Suffering and Its Explanation in Couples Impacted by Breast Cancer: Development and Testing of an Explanatory Model

Wenjia Liu

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Reading Committee:

Frances Marcus Lewis, Chair

Ira Kantrowitz-Gordon

Monica Oxford

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Abstract

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Wenjia Liu

Chair of the Supervisory Committee:

Frances Marcus Lewis

Department of Child, Family, and Population Health Nursing

Background: Suffering is a universal human experience. However, its definition fails to reflect the most recent evidence and does not reflect a comprehensive review of the concept. Both women with breast cancer and their intimate significant other experience significant psychological suffering, and growing evidence has shown that couples often cope with breast cancer jointly as a system rather than as individuals. However, there is very little known about the ways in which couples cope with breast cancer as a dyadic system. Further, little is known about which specific forms of common dyadic coping are linked to less psychological suffering and better health outcomes. Also less well understood is whether and what types of couples' congruence in common dyadic coping relate to better health outcomes.

Purpose: This three-study dissertation aims to fill these gaps by 1) conducing a comprehensive review and analysis of the concept of suffering and proposing a definition that integrates current studies and analyses of suffering; 2) developing a new measure of common dyadic coping; and 3) examining the associations between the magnitude and types of common dyadic coping, congruence in common dyadic coping, and psychological suffering in women with breast cancer

and their spouse caregivers.

Methods: The first study of this dissertation used Rodgers' evolutionary approach to guide the concept analysis. The second and third study were secondary analyses using baseline data of a recently completed randomized clinical trial, Helping Her Heal, which tested the efficacy of a five-session psycho-educational intervention targeting marital communication and interpersonal support. Participants include 343 women with early-stage breast cancer and their 343 spouse caregivers. Women were eligible if they were diagnosed within the past eight months; married or in an intimate relationship with her spouse caregiver for at least six months; could read and write English; and lived within 100 miles of the study center. Spouses also need to speak English and reside in the same residence to be eligible. Measurement construction in Study 2 involved three phases: 1) an expert panel review to confirm the conceptual fit of items to measure common dyadic coping extracted from the Mutuality and Interpersonal Sensitivity Scale used in the completed clinical trial; 2) exploratory factor analysis to identify the factorial structure of the new measure; and 3) confirmatory factor analysis to examine goodness of fit of the identified factorial model. In Study 3, the Center for Epidemiologic Studies-Depression Scale and the Spielberger State-Trait Anxiety Inventory were used to measure psychological suffering. Common dyadic coping was assessed by the new measure developed in Study 2. Congruence in common dyadic coping was assessed by the absolute difference between women's and spouses' common dyadic coping scores. Multiple linear regression and path analysis were used to examine the relationship between these variables.

Results: In Study 1, 172 articles out of initially identified 5628 records were included in the concept analysis. Analysis identified nine attributes of suffering (universal and unavoidable, individualized and subjective, multidimensional, overwhelming negative emotion, considerable

duration and intensity and dynamic, loss of control, crisis of meaning and meaning making, unspeakable, and loneliness), three antecedents of suffering (capacity to perceive suffering, threats to the soundness/intactness/homeostasis of the person, and considerable magnitude beyond the person's threshold to bear and cope), and two types of consequences of suffering (negative and positive). Study 2 generated a 12-item, 4-factor measure of common dyadic coping with a particular focus on open communication (CDC-C). The four factors include: Keeping the communication open with each other about breast cancer; Sharing a positive outlook on breast cancer; Avoiding discussion of negative thoughts and feelings about breast cancer; and Spending sufficient time together talking about breast cancer. Model fit was satisfactory for both diagnosed women and spouses, and internal consistency reliability indicated by McDonald's omega was acceptable. Study 3 found that higher level of common dyadic coping predicted lower psychological suffering in both diagnosed women and spouses. Greater congruence in common dyadic coping also predicted lower psychological suffering. Different types of common dyadic coping and its congruence related to different outcomes in women and spouses.

Conclusions: This dissertation generated a comprehensive definition of human suffering that provided a conceptual foundation for future research, including development or refinement of assessment tool of suffering, testing theoretical models, and developing theory-based interventions to alleviate suffering. It also generated a new measure that can be further validated and used to assess couple's joint communication efforts to deal with shared stressor in future research. Further, it created important implications for health care in couples facing breast cancer that higher use of open communication and sharing a positive outlook and less use of avoidance coping have potential to enhance psychological adjustment.

TABLE OF CONTENTS

LIST OF FIGURES

LIST OF TABLES

Chapter 1: Introduction

Suffering is a universal and ineluctable aspect of human's life (Condon, 2013; Daly, 1994; Doucet, 2014; Duarte-Quilao & Strüby, 2018). It "profoundly touches upon the deepest aspects of human soul and human experience" (VanderWeele, 2019). The richness of a human's life is an advantage but also brings more vulnerability to suffering in deeper and more sophisticated ways (Svenaeus, 2014). The inherent comprehensive, all-embracing, perplexing, and intangible nature of this phenomenon makes it extremely difficult to define and research on (Büchi et al., 2002; Frank, 2001; Lohne, 2008; Schulz et al., 2010; Williams, 1940).

The efforts to conceptualize suffering have started more than eighty years ago, when Williams (1940) first defined suffering as a meaning-driven human experience that involved acute strain and a feeling of dissatisfaction. Among many attempts to define suffering, Cassell's definition that perceived suffering as a distressful state when the integrity of the person is threatened was most widely acknowledged (Cassell, 1982). Cassell stood for wholistic personhood as opposed to the mind-body dichotomy tradition in biomedicine, and proposed alleviation of suffering as the goal of medicine (Cassell, 1998). After Cassell, the most rigorous analysis of suffering was seen in the work of Rodgers and Cowles (1997), who claimed that suffering was "an 'individualized', 'subjective' and 'complex' experience characterized primarily by a person's assigning to a situation or perceived threat an intensely 'negative meaning'" (p.1050). The most recent comprehensive research on the concept of suffering was by Best and colleagues (Best et al., 2015) in which they systematically reviewed 128 articles related to adults' suffering published between 1992 and 2012, yet the scope was limited to negative response to suffering in cancer patients. After 2012, new research evidence has advanced our understanding of suffering, however, an updated review is lacking to reflect these changes.

Compared to conceptualization of suffering, theoretical models of suffering were much

fewer, let alone testing the models with empirical research. Examples of suffering models include the intrapersonal process of suffering (Sacks, 2013), model of an integrated view of suffering (Krikorian & Limonero, 2012), and the existential-experiential model of suffering in palliative care patients (Beng et al., 2014). Only Krikorian & Limonero's integrated model of suffering from the perspective of stress and coping has been tested with empirical research (Krikorian et al., 2014), which revealed that adjustment problems as a result of adopted coping strategies in response of psychological distress were the reason of suffering in cancer patients.

To gain a better understanding of suffering and the mechanism of its occurrence, this dissertation started with a comprehensive review of conceptual and empirical studies of suffering in the literature and aimed to generate an integrated definition and theoretical model of suffering from it. This part was reported in Chapter 2. In the second part of this dissertation, the theoretical model of suffering was partially tested with single-occasion baseline data from a recently completed randomized clinical trial targeting marital communication and interpersonal support in women diagnosed with early-stage breast cancer and their spouse caregivers. This part was reported in Chapter 4. In order to generate the measure for the construct of "coping" in the model to be tested, an intermediate study was conducted to construct the measurement tool for common dyadic coping, referring to the conjoint efforts of the couple to cope with breast cancer. This part was reported in Chapter 3. In each Chapter, the study background, aims, methods, results, discussion of the findings, and conclusion were successively presented, followed by the reference list. Attached in the end were created Figures and Tables that helped with better demonstration of the study results. In the last Chapter, main findings are synthesized along with a description of the implications of this work for future research and health care practice.

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Chapter 2: Refreshing Our Understanding of Human Suffering: A Comprehensive Review and Concept Analysis

Abstract

Background: Suffering is a universal human experience that has received inadequate attention. Despite multiple attempts to conceptualize suffering, the concept remains elusive and its definition have failed to change over time in response to new evidence. The purpose of this paper is to systematically analyze the concept of suffering and integrate the newest evidence to what was previously claimed.

Methods: PubMed, Embase, CINAHL, PsycINFO, Scopus, Web of Science and ProQuest Dissertations & These Global were searched using keywords "suffering" combined with (concept* OR theor* OR defin*) in title or abstract. Journal articles or book chapters that were relevant to conceptualization of suffering in adult patients were included. Of 5628 initially identified records, 137 were selected. Adding 35 articles identified by manual search, a total of 172 articles were included in the analysis. The surrogate terms, relevant uses, and attributes, antecedents, and consequences of the concept were extracted. A review of the evolutionary development of this concept and comparative analysis with related concepts (e.g., pain, trauma) and potential opposite concepts (e.g., happiness, euthymia) were also conducted to help understand the concept.

Results: Analysis yielded the following essential attributes: universal and unavoidable, individualized and subjective, multidimensional, overwhelming negative emotion, considerable duration and intensity, loss of control, crisis of meaning & meaning making, unspeakable, and loneliness. There are three antecedents of suffering: capacity to perceive suffering, threats to the soundness/intactness/homeostasis of the person, and considerable magnitude beyond the person's threshold to bear and cope. Both negative and positive consequences of suffering were identified. Suffering is defined as *"an overall negative affective state characterized by strong and enduring*

negative emotions, perceived loss of control, wordlessness, loneliness, meaninglessness, and the desire to make sense of their experience. It occurs when a sentient person feels their fundamental needs or core life values/goals are threatened or failed to be fulfilled, and the intensity of the negative emotional state is beyond their threshold to bear and cope."

Conclusion: Suffering is an overall negative affective state where negative emotions outweigh positive ones and their intensity exceeds the person's threshold to bear. It is a consequence of disrupted basic human needs or core life goals. It is important to pay attention to the transformative power of suffering rather than considering it as purely negative. Not to pathologize suffering but embracing it as part of life is potential to promote healing and well-being.

Key words: human suffering, definition, concept analysis, adult patients, health care

Introduction

Suffering is a universal and ineluctable aspect of human life (Condon, 2013; Daly, 1994a; Doucet, 2014; Duarte-Quilao & Strüby, 2018; Duffy, 1992; Eriksson, 1992; Maris, 1981) and profoundly affects the deepest parts of human experience (VanderWeele, 2019). Suffering is more prominently manifested on patients. The English word 'patient' means 'one who is suffering' in its Latin origin. The identification and alleviation of suffering is widely acknowledged as the essential goal of medicine and the cornerstone of nursing and caring (Cassel, 1982; Daneault et al., 2004; Eriksson, 1992; Lindholm & Eriksson, 1993; Lohne, 2008; Wittmann et al., 2009).

Despite the pervasiveness of suffering in human life and health care, the concept is not widely addressed (Best et al., 2015; Kahn & Steeves, 1986; Rodgers & Cowles, 1997). The inherent comprehensive, all-embracing, perplexing, and intangible nature of this phenomenon makes it extremely difficult to define and on which to conduct research (Büchi et al., 2002; Frank, 2001; Lohne, 2008; Schulz et al., 2010; Williams, 1940). Substantial effort has been attempted to understand and define suffering but its definition and attributes remain elusive and difficult to articulate (MacKintosh, 2013; Tate & Pearlman, 2019). No consensual definition exists that captures all its constituents (Bustan, 2019), which has impeded empirical research (Best et al., 2015; Wittmann et al., 2009). The emergence of new research evidence mandates the need to update our understanding to human suffering.

Toward that end, the aims of this study were to: 1) review the extant definitions of suffering along with its historical evolution; 2) update the attributes, antecedents and consequences of suffering based on classic and recent literature; 3) propose a new integrated definition of suffering; 4) compare suffering to its related and opposite concepts; and 5) generate

implications for future research and health care practice. Taking Rodgers' evolutionary view of concept analysis (Rodgers, 1989), our goal is not to generate a unified, 'golden' definition of suffering with a fixed set of essential characteristics, but rather to update our understanding of the concept so that it reflects the current state of science and informs future research.

Methods

Literature Search & Selection

A systematic literature search was conducted in PubMed, Embase, CINAHL, PsycINFO, Scopus, Web of Science and ProQuest Dissertations & These Global using keywords "suffering" combined with (concept* OR theor* OR defin*) in title or abstract, filtered by English language and published up to April 16, 2021. Since the literature scope of Scopus, Web of Science and ProQuest Dissertations & Theses Global was too comprehensive, searches in these databases were refined by limiting to relevant subjects (e.g., nursing, medicine, psychology, social sciences, etc.). Peer-reviewed journal articles which were relevant to conceptualizing suffering in adult patients in health or in a health care context were included. Books, book chapters, theses and dissertations, and studies about measurement and coping of suffering were included only if highly relevant content was found.

Of 5628 initial records identified from the databases, 3300 were screened for title and abstract. After removing duplicates and ineligible records that focused on nonhuman (animal) suffering, children's or adolescents' suffering, suffering of caregivers/health care professionals/witnesses/war or disaster survivors or in disciplines of biology, theology, philosophy, literature, politics, law and ethics without a linkage to health care context, 277 remained for full text review. After full text screening, 137 items were included. An additional 35 items were identified through manual search, resulting in a total of 172 items that were

included for data extraction and analysis. **Figure 2.1** contains a summary of the literature search and selection process.

Data Extraction

Using Rodgers' evolutionary approach (Rodgers, 1989; Rodgers & Knafl, 2000), we identified the surrogate terms and relevant uses of the concept. From each included article, we extracted information about the concept's attributes, antecedents, and consequences, and then clustered and analyzed extracted information for emergent themes. The themes representing suffering's attributes and antecedents were integrated and used to propose a definition of human suffering. We also reviewed the evolutionary development of the concept and compared it with related and opposite concepts.

Results

Surrogate Terms and Relevant Uses of the Concept

Surrogate terms are words that are used interchangeably to express the same idea (Rodgers & Knafl, 2000). Surrogate terms used for suffering included: discomfort, displeasure, discontent, distress, anguish, affliction, torment, pain, psychache, soul pain, total pain, heartache, agony, misery, and trauma (Best et al., 2015; Morse, 2001; Rodgers & Cowles, 1997). The concept of suffering has been widely used in medicine, nursing, psychology, psychiatry, sociology, philosophy, literature, theological and religious literature, morality and ethics.

Evolution of the Definitions of Suffering

Definitions of concepts evolve over time and include its origins, development, and current status, deepening understanding of the temporal and contextual aspects of the concept (Rodgers & Knafl, 2000). The current analysis yielded 35 definitions of suffering (see **Table 2.1**). Definitions were highly heterogeneous and did not include a core or universal definition that was

used. Publications ranged from 1940 to 2021, with the majority published before 2000 or after 2010. Disciplines mainly encompassed nursing, medicine, psychiatry, psychology, bioethics, and public health. The definitions were proposed by Western countries, including USA, Canada, Australia, and Europe.

Prior to 1982 the concept of suffering did not receive much attention by health professionals, likely due to the dominance of the biomedical model in medicine. At that time, Cassell published his seminal work on suffering which shifted the focus of medicine from *body* to *person* and the goal of medicine from treating physical symptoms to relieving suffering. Cassel believed suffering was a subjective experience and occurred when the intactness of a person was threatened (Cassell,1982, 1991a, 1998, 1999). Apart from threat to a person's integrity, other scholars attributed suffering to pain, injury, loss, compromised quality of life, frustrated goals, unachieved wished-for state, or what was called an 'acceptability gap' (Cherny et al., 1994; Copp, 1974; Coulehan, 2009; Fordyce, 1988; MacKintosh, 2013; Schmitt, 1981; van Hooft, 1998a). While most scholars favored Cassel's view that suffering was *subjective* and could not be assessed independent of the sufferer, van Hooft (1998a) viewed suffering as *objective* which could exist even if the person had no conscious awareness of it.

In 1997, Rodgers and Cowles's concept analysis spotlighted a person's assigned negative meanings to the threat as a key attribute of suffering. *Meaning* was also emphasized in other definitions of suffering (Best et al., 2015; Cassell, 1991b, Williams, 1940; Yager, 2021). The importance of meaning was heavily influenced by the classical work of Frankl who claimed that "suffering ceases to be suffering at the moment it finds a meaning" (Frankl, 1963, p.115).

Chapman and Gavrin (1993) added a *coping* component to suffering by proposing that suffering involved "exhaustion of psychosocial and personal resources for coping" (p.11).

Krikorian and Limoner integrated previous stress and coping theories and put forward a new definition of suffering. They claimed that suffering was experienced when the regulatory processes normally adopted by the person did not lead to adaptation but exhaustion in front a threat (Krikorian & Limonero, 2012).

A noticeable cluster of definitions was generated from studies exploring the lived experience of suffering using Parse's human becoming theory and research methods (Baumann, 2016; Daly, 1994b; Doucet, 2014; Duarte-Quilao & Strüby, 2018; Hart, 2018; Pilkington & Kilpatrick, 2008). While most other definitions viewed suffering as overwhelmingly negative, this school of thought focused on the transforming, liberating, and brightening power of suffering. This meant that new meanings, possibilities, and opportunities emerged from suffering.

More recently MacKintosh (2013) added that suffering occurred when there was an "acceptability gap." This meant that failing to accept the current status led to suffering. Svenaeus (2014) claimed that suffering was mainly related to frustration in three areas: a person's way of existing and engaging in the world, relationship with others, and core life values. Aguilera (2020) proposed an interesting definition of suffering based on the global workspace model of human consciousness, regarding suffering as an overall negative emotion valence. Yager (2021) proposed that suffering occurred when fundamental human needs were affected such as biological health, food, housing, interpersonal needs, and meanings in life.

Attributes of Suffering

In the Oxford English Dictionary, suffering is defined as *"the state of undergoing pain, distress, or hardship"* (Oxford Living Dictionaries, n.d.). Merriam-Webster Dictionary defined it as *"conscious endurance of pain or distress"* or *"pain that is caused by injury, illness, loss, etc.:*

physical, mental, or emotional pain" (Merriam-Webster Dictionary, 2021). According to the Online Etymology Dictionary, suffering comes from Latin *"Sufferre"*, composed of "*sub*-" meaning "under, below", and "*ferre*" meaning "to carry, bear." Suffering means undergoing something you must bear (Online Etymology Dictionary, n.d.). Eriksson (1992) also pointed out the Latin words "passio" and "dolor" (pain, sorrow, grief) and the Greek word "pascho" (to undergo, to be affected) that may refer to suffering.

The attributes of a concept are the defining characteristics of the concept of interest (Rodgers & Knafl, 2000). Based on the current analysis, nine attributes of suffering were identified, briefly described below.

Universal and unavoidable. Suffering is as an inevitable human experience, an indispensable part of life (Arman & Rehnsfeldt, 2003; Cutcliffe et al., 2015; Eriksson, 1992, Frankl, 1963; Kellehear, 2009). Suffering consists of every painful or distressful experience that must be faced (Lohne, 2008). It has existed in human history since the beginning of human existence (Beng et al., 2014). As one participant at the end of life stated, *"To be fully human means to suffer"* (Bruce et al., 2011, p.3). In another interview study of patients with advanced cancer in palliative care, participants mentioned suffering as a normal part of daily life which can be experienced by everyone at certain point. One patient said that *"Everyone suffers, whether it's from cancer or relationships… everyone suffers. … So why should we be any different? … I see it as the norm. … Everyone – if you look into their life – they've got something that cause*s *them pain. … whether it's physical pain or emotional pain, they've got something. … And it's suffering!"* (Ellis et al., 2015, p.202)

Individualized and subjective. Suffering is a "personal matter - something whose presence and extent can only be known to the sufferer" (Cassell, 1991a, p.35). It is a private

experience unique to each individual and can vary from person to person (Kahn & Steeves, 1995; Rodgers & Cowles, 1997). The assessment of suffering is also subjective. Suffering occurs only when *the involved individual* perceives the experience as threatening (Cassel, 1982) and only the person themselves can report the intensity of suffering and whether it is unbearable (Cassell, 1982; Edwards, 2003; Ruijs et al., 2009). Another aspect supporting the subjectivity of suffering is the relation of the experience's *meaning* to the person (Cassell, 1982). The distinct value and belief system as well as the prioritization of the person's concerns determine what an external stimulus *signifies* to the person. Therefore, even under very similar circumstances, based on different *interpretations*, some people may suffer while others may not (Cassell, 1999; Mendonça et al., 2021). For instance, the neurologic deficits of early multiple sclerosis can be catastrophic for a cellist but might not have as many ramifications to a scholar (Cassell, 1999).

Suffering is also individualized, requiring different adjustment and coping by each person in front of a threat, depending on their supportive resources and regulatory capacity (Montoya-Juarez et al., 2013). In addition, suffering is historically, culturally, and socially context bound (Best et al., 2015). For example, suffering of a Christian patient with an end-of-stage illness in the U.S. may manifest more in the existential and spiritual dimensions, while people living with HIV in rural Zimbabwe may experience more social suffering because of stigma, poverty, and lack of access to health care.

Although most scholars endorse suffering as subjective, a few scholars hold an opposite view. Van Hooft (1998a) asserted that suffering is objective and requires no conscious awareness of the sufferer. He claimed that Cassell's view of subjective suffering cannot account for the suffering of persons who lack insight on their experience. Stump (2010) proposed that suffering is both subjective and objective, favored also by Tate and Pearlman (2019). The latter argued

that individuals are not always the best judge of their experiences from a standpoint of social ethics. For example, a person with substance use disorder who obtained heroin via prostitution or a child who does not understand what is happening in a sexual abuse may deny any suffering and even feel happy. However, it does not mean they are not suffering in certain important ways (Tate & Pearlman, 2019).

Multidimensional. Suffering is multidimensional because a person is a holistic being with physical, cognitive, affective, mental, psycho-spiritual, existential, relational/interpersonal, sociocultural, and political components (Beng et al., 2014; Best et al., 2015; Egnew, 2009; Kahn & Steeves, 1995; Krikorian et al., 2012; Rodgers & Cowles, 1997; Schulz et al., 2010; Wilson et al., 2007). Suffering involves "the total self" (Duffy, 1992, p.299) and "can occur in relation to any aspect of the person" (Cassell, 1998, p.131). Some patients in palliative care described suffering as "total pain" (Mehta & Chan, 2008). As Svenaeus articulated, suffering *"involves the person's entire life: how she acts in the world, communicates with others, and understands and looks upon her priorities and goals in life. … not only one's body but also other things in the world that prevent one from having a good (enough) life and being the person one wants to be."* (Svenaeus, 2014, p.419)

Physically, suffering can be manifested as pain, disability, nausea, weakness or fatigue, dyspnea, lack of appetite, insomnia, or changed/altered body image (Benedict, 1989; Hamid et al., 2021; Krikorian et al., 2012; Martins & Caldeira, 2018; Mendonça et al., 2021; Schulz et al., 2010; Wilson et al., 2004). *Psychologically,* it can be present as depression, anxiety, alienation, sadness, loss of control, fear, anger, guilt, or feeling like a burden to others (Beng et al., 2017; Krikorian et al., 2012; Martins & Caldeira, 2018; Schulz et al., 2010; Wilson et al., 2004). In the *social-relational dimension*, people can suffer from communication problems, interpersonal

conflict, violence, physical or emotional abuse, financial problems, lack of access to health care, and social isolation or discrimination (Benedict, 1989; Hamid et al., 2021; Ruijs et al., 2009; Yager, 2021).

Existential suffering. The founder of logotherapy, Austrian psychiatrist and psychotherapist Viktor Frankl, pointed out that a search for meaning is a person's primary task in life; when this task is frustrated, the person will suffer from "existential frustration" (Frankl, 1992). Existential suffering, also called existential pain or existential distress, is related to the meaning, purpose, value, hope and futility of life, and freedom, authenticity, and autonomy (Boston et al., 2011; Eriksson, 1992; Grech & Marks, 2017). It regards what matters most for the person and the goals and values the person pursues to sustain meaning in life (Kissane, 2012). People with existential suffering experience loss of meaning or purpose in life; loss of true self or authentic living; feelings of worthlessness, hopelessness, helplessness; loss of motivation; loss of autonomy or self-esteem; social isolation, and loneliness (Blinderman & Cherny, 2005; Gilot, 2008; Grech & Marks, 2017; Mendonça et al., 2021; Morita et al., 2000; Ruijs et al., 2009; Schulz et al., 2010; Vehling & Kissane, 2018).

Spiritual suffering. Spiritual suffering is a conceptual subtype of existential suffering (Grech & Marks, 2017). Spiritual issues involve faith and religious beliefs, value system, hope peace, inner strength, transcendence, reconciliation and harmony. It also involves interconnectedness between self or soul and others, nature, art, and a higher being of power (e.g., God, the sacred, the divine) (Boston et al., 2011; Egnew, 2005; Jaberi et al., 2019; Salander, 2018; Teixeira, 2008; Villagomeza, 2005). Spiritual suffering (or distress/pain/crisis) can be manifested as shaken profound belief and value system; impaired connectedness to self, others, or the higher power; impaired inner peace and harmony; and loss of hope (Agrimson & Taft,

2009; Anandarajah & Hight, 2001; Caldeira et al., 2013; Murata, 2003; Villagomeza, 2005).

Cultural dimension. Cultural factors can be a source of people's suffering. A person's cultural background influences their beliefs and values, health behaviors, and the meaning they may ascribe to an illness and other adverse circumstances (Cassell, 2004; Krikorian et al., 2012; Papadopoulos, 2007). Cultural norms also influence family dynamics and the caregiver role (Krikorian et al., 2012). For instance, in Asian countries the family members of an ill person may take on caregiving responsibility more automatically based on the cultural expectations, while Western families are more inclined to respect the patient's autonomy (Best et al., 2015). Therefore, a person from an Asian family may suffer more considering the caregiving burden his/her illness brought to the family. Additionally, the broader sociocultural environment affects how an ill person is perceived and treated by the society. Patients diagnosed with stigmatized diseases can be repelled and isolated and suffer more while less stigmatized illnesses can be more acceptable and not incur suffering to patients (Cassell, 2004; Mendonça et al., 2021).

Overwhelming negative emotion. Suffering is perceived as negative, unpleasant, painful, aversive, anguishing and heart-wrenching experience that is generally unwanted (Beng et al., 2014; Bueno-Gómez, 2017; Doucet, 2014; Egnew, 2009; Meerwijk & Weiss, 2011; VanderWeele, 2019). Tate and Pearlman described this distinctive nature of suffering as 'a sustained negative feeling' (Tate & Pearlman, 2019, p.106). People usually deny it, avoid it, and prefer not to be involved in it (Edwards, 2003; Luboshitzky, 2008). Once suffering, people often feel it unbearable and struggle to get rid of it (Ruijs et al., 2009).

However, suffering is not exclusive of positive emotions; rather, it is a status where negative emotions are too overwhelming to be offset by positive emotions. According to Mayerfeld (1992) and Aguilera (2020), suffering does not deny the existence of concurrent

positive feelings - Happiness and suffering of a person are always on a continuum, wherein suffering represents an *overall* affective state in which negative feelings *outweigh* positive thoughts and sensations in a person (Aguilera, 2020; Mayerfeld, 1992). Cutcliffe et al. (2015) pointed out that viewing suffering as purely negative leaves little space for individuals' growth and development.

There are circumstances in which suffering contains positive meanings. For example, one may be able to bear suffering in order to achieve something worthier. Suffering becomes something positive when given a transcendent, significant meaning, such as 'thinking of it as [a sacrifice] for the ultimate good' (Van Hooft, 1998b, p.15). Nietzsche favored suffering and regarded the willingness to put up with suffering as a means to achieve a higher order of noble humanity as opposed to the avoidance of suffering that indicates degradation of the human spirit (van Hooft, 1998b). Art and some religions such as Christianity elevate suffering as something good to achieve creation or salvation (van Hooft, 1998b; Williams, 1940). Suffering is also an essential part to fulfill a person's integrative life. From the humanbecoming perspective, suffering can be transformative in impelling people to reflect on their taken-for-granted ordinary life and begin to think differently (Doucet, 2014; Duarte-Quilao & Strüby, 2018). People in suffering may obtain a heightened and enriched life experience as well as empathy or compassion to others' suffering (Eriksson, 1992; Van Hooft, 1998b; Williams, 1940). It is even possible that individuals actively seek suffering in order to achieve desirable goals. Mosak and colleagues mentioned three categories of sufferers proposed by Berne (1964; Mosak et al., 1994). For the first category of sufferers, suffering is both involuntary and unwelcomed. For the second category, suffering is also involuntary but embraced by the sufferers. In the third category, sufferers actively seek suffering for the sake of certain outcomes in which the gain overweighs

the pain (Mosak et al., 1994). However, these positive perceptions of suffering cannot erase the intrinsically negative nature of suffering, namely, people's painful feelings in suffering are real.

Considerable duration and intensity and dynamic. Suffering has a temporal element (Barrett, 1999; Cassell, 1998). It has considerable duration and intensity (Edwards, 2003; VanderWeele, 2019). While distress can be fleeting, suffering "implies both greater chronicity and higher intensity of anguish" (Yager, 2021, p.1). Suffering takes time to resolve and its impact is not short-lived but enduring (Meerwijk & Weiss, 2011; Van Tongeren & Van Tongeren, 2021). In addition, the state of suffering is dynamic. It can vary and fluctuate in intensity along the trajectory (Best et al., 2015; Ruijs et al., 2009).

Loss of control. Suffering people often lack a sense of control (Fredriksson & Eriksson, 2001), or a feeling of unmanageability, where previous coping strategies and regulatory system no longer apply (Leach & Kelemen, 1987; Krikorian & Limonero, 2012). For example, in a qualitative study of patients at the end of life, participants reported a sense of *groundlessness*, where their belief system was shattered, and they were not able to reconcile the suffering experience with their original world (Bruce et al., 2011). Sufferers often cannot control the occurrence, duration and intensity of their suffering (VanderWeele, 2019). In unbearable suffering, life was described as "chaotic" in which patients lost their grip on it (Andermo et al., 2018). They may feel stuck, overwhelmed, exhausted, powerless, helpless and hopeless (Barrett, 1999; Bolger, 1999; Best, Aldridge, Butow, Olver, & Webster, 2015; Cassell, 1998). Like one patient in Daly's study shared, *"it was excruciatingly painful… I felt terribly empty, enormously angry… and, and yet helpless in terms of how one might change that because I was stuck with it…"* (Daly, 1994b, p.256). These uncomfortable feelings lead to a desire to establish an order and a sense of safety out of it (Andermo et al., 2018).

Results from an experimental study showed that the transition from pain to suffering occurred when patients felt out of control, and the controllability over pain reduced the magnitude of perceived suffering (Löffler et al., 2018). Many other empirical studies support the loss of control as a defining characteristic of suffering (Andermo et al., 2018; Bolger, 1999; Charmaz, 1983; Dildy, 1996; Heine et al., 2012; Mendonça et al., 2021; Nayak et al., 2018; Ruijs et al., 2012). This feeling of loss of control may result from uncontrollable pain, unstoppable progressive deterioration from disease, damaging effects of treatment, restricted physical and life activities, loss of normal functioning, undermined social roles, increased dependence on others and feeling of being a burden to the society, and feeling useless due to loss of autonomy and dignity (Charmaz, 1983; Dildy, 1996; Mendonça et al., 2021).

Crisis of meaning and meaning making. Multiple studies revealed that suffering people felt meaningless (Best et al., 2015), a lack or loss of meaning in life (Andermo et al., 2018; Caldeira et al., 2013; Grech & Marks, 2017; Leach & Kelemen, 1987; Yager, 2021) or "a crisis of meaning" (Barrett, 1999, p.465). As a woman suffering from breast cancer described, *"suddenly life no longer makes any sense"* (IACOB, 2011, p.509). Research showed that patients reporting a diminishing sense of meaning were inclined to suffer more (Loeffler et al., 2018). Every person has basic beliefs and assumptions toward the surrounding world (Cassell, 1991b), a working schema to make sense of the world (Taylor & Crocker, 1981). When misfortune strikes, the sufferer experiences a 'meaning discrepancy' - their previously held schemas were no longer able to explain what was going on to them, shattering their basic assumptions and world to be incomprehensible and absurd (Cassell, 2004; Heine et al., 2006; Li et al., 2016; Janoff-Bulman, 2004; Van Tongeren & Van Tongeren, 2021).

Humans are meaning-makers (Frankl, 1992; Janoff-Bulman, 2004; Heine et al., 2006). Facing adversity, the crisis of meaning triggers the person's attempts to find meaning in their suffering (Andermo et al., 2018; Bentur et al., 2014; Saarnio et al., 2012; Van Tongeren & Van Tongeren, 2021). As Janoff-Bulman (2004) precisely summarized, people usually struggle with two types of questions: *meaning as comprehensibility* ("Why this happened?" "Why this happened to me?") (Bäärnhielm, 2000; Gammeltoft, 2006; Grech & Marks, 2017; IACOB, 2011; Williams, 1940) and *meaning as significance* ("What does this mean to me?" "What is the significance of my experience?") (Grech & Marks, 2017; IACOB, 2011). Once meanings were found, suffering could be significantly reduced (Bäärnhielm, 2000; Cassell, 2004; Fredriksson & Eriksson, 2001). As Frankl said, "Man is ready and willing to shoulder any suffering as soon and as long as he can see a meaning in it." (Frankl, 1961, p.25). Kirmayer echoed this: "The meanings given to symptoms and distress can transform suffering. Meaning - *any* meaning – serve to turn back the tide of chaos and bafflement that confronts us in affliction" (Kirmayer, 1994, p.183). The good thing is, a person can *choose* the meaning *given* or *assigned* to their experience (Cassell, 2004; Daly, 1994a; Rodgers & Cowles, 1997). Therefore, one can change the assigned meanings to ameliorate suffering (Cassell, 1982; Kahn & Steeves, 1986; Taylor, 1983).

Unspeakable. Suffering is unspeakable, hard to grasp and is often unshareable (Wilkinson, 2005, cited by Miles et al., 2011). The suffering person often has no words to adequately express what they are going through (Stanley, 2006; Svenaeus, 2014). Sufferers are submerged in their enormous pain or overwhelming aversive emotions and become speechless; their voices seem to be muted, even though some may be screaming (Reich, 1987, 1989). Frank has spoken up from a patient's point of view: *"our suffering was what we could not say. We*

feared saying what we felt, and we feared our words could never convey what we felt but would reduce those feelings to complaints and specific concerns." (Frank, 2001, p.354). In a qualitative study among patients with terminal cancer, one patient said, *"I was so sick, that's what happens, you get to a point of such vulnerability, there are no words to convey just how vulnerable you become"* (Daneault et al., 2004, p.9). Neurophysiological evidence supported the speechlessness in sufferers by showing that traumatized individuals' brain activities overseeing semantic processing and language articulation slowed (Van der Kolk, 2015; Solomon & Heide, 2005).

Goldberg (1986) noted that suffering is often "borne silently and alone" (p.97), and there seems to be a 'silent conspiracy' suggesting suffering should be kept private (p.98). This conspiracy may prevent sufferers from speaking out their suffering with family, friends, even health care professionals (Daly, 1994a). Patients may need the health care providers' assistance to help them speak out. However, health care workers seem also to share this 'conspiracy of silence,' for finding it uncomfortable to talk about, not being prepared to face it, or lack of confidence to help patients deal with it (Best et al., 2015; Cassell, 1999; Rodgers & Cowles, 1997). In addition, worrying about troubling others or causing others' sadness can also mute the sufferers (Barrett, 1999; Fredriksson & Eriksson, 2001). For example, in a qualitative study exploring the lived experiences of women with breast cancer in Kashmir, one patient shared that "*Sometimes, I felt like my mind will burst because there was so much in my mind, which I was not able to share with anyone. I did not want to hurt anyone or make them sad"* (Hamid et al., 2021, p.688). The broader sociocultural environment can also create barriers for sufferers to speak up, especially when keeping suffering for oneself is regarded as socially favorable, the incapacity to cope with one's negative emotions is believed shameful (Barrett, 1999), or when the patient's illness or health condition is culturally stigmatized (Leyva-Moral et al., 2015;

Hamid et al., 2021; Mendonça et al., 2021).

Loneliness. Suffering individuals often feel disconnected, isolated, alienated, abandoned, and lonely (Best et al., 2015; Grech & Marks, 2017; Martins & Caldeira, 2018; Tate & Pearlman, 2019). Illness can result in restricted physical activities and social life. As a result, earlier interpersonal relationships and social networks gradually wane or are destroyed, leading to patients' loneliness (Charmaz, 1983). Inattentiveness and ignorance from previous friends and relatives and being devalued and even objectified by others, can hurt patients' feelings and make them voluntarily withdraw from social connections (Charmaz, 1983; Martins & Caldeira, 2018; Sacks, 2013).

Because suffering is intimate and difficult to articulate, it also aggravates the sense of loneliness. Sufferers often feel the inability to share their feelings and communicate with others the meanings of their suffering and their inner needs (Pilkington & Kilpatrick, 2008; Sacks, 2013; Tate & Pearlman, 2019). *"It's hard to explain. I can't tell you what it's like. You have to go through it. I don't know if there are any words"* (one participant said in Pilkington & Kilpatrick's study). Not to be understood by other people contributes to sufferers' isolation and loneliness (Andermo et al., 2018; Baumann et al., 2013; Hart, 2018). Patients with cancer or chronic pain in the study by Andermo et al. described their suffering as 'a lonely struggle,' and used a 'shelter' or 'wall' to delineate the relationship with their surroundings. In Hart's study, a participant stated, *"Nobody can remotely come close to understanding how devastated and heartbroken and ravished my soul feels"* (Hart, 2018, p.142).

Loneliness intensifies when patients' illness is stigmatized, as in HIV/AIDS or psychiatric disorders (Miles et al., 2011; Yager, 2021). Patients feel ashamed to disclose their disease and therefore opt to remain silent alone. On the other hand, some patients may choose to endure their

suffering alone in order to avoid bringing suffering to people close to them, as patients with cancer hide their diagnoses and chemotherapy to intimates and relatives (Mendonça et al., 2021).

Despite this extreme loneliness and even voluntary withdrawal from social interactions, suffering patients desire connecting and communicating with other people. Parse proposed a paradox of *'connecting-separating'* in her human becoming theory (Parse, 1992), which captures the oscillating state of a suffering person who moves toward and apart from others simultaneously (Daly, 1994b). On the one hand, the presence and support of other people is desired; on the other hand, sufferers still feel strong loneliness even when they are surrounded by other people, and they may choose to keep others at a distance (Daly, 1994b; Doucet, 2014; Duarte-Quilao & Strüby, 2018; Pilkington & Kilpatrick, 2008; Hart, 2018).

Antecedents to Suffering

Antecedents are necessary characteristics that lead to the occurrence of a concept (Rodgers & Knafl, 2000). This analysis discovered three antecedents to suffering: 1) capacity to perceive suffering; 2) threats to the soundness/intactness/homeostasis of the person; and 3) incapacity or lack of resources to cope with the threat.

Capacity to perceive suffering. Because most scholars believe suffering is a perceived subjective experience, in order that suffering occur, a person must be sentient and have the capacity to perceive suffering, a sense of future and past, and awareness of humanity (Aguilera, 2020; Cassell, 1991b, 2004; Leach & Kelemen, 1987; Rodgers & Cowles, 1997; Steeves & Kahn, 1987). Given this, an early-stage fetus before eighteen weeks is not able to suffer because sentience has not developed (Tawia, 1992).

A person in a vegetative state may still be able to suffer if this person is sentient though unconscious (Austriaco, 2016). Interestingly, Mayerfeld (1992) argued that when people are

overly occupied by fear, shame, or hate, they may not be able to know they are suffering at that moment, although they may get that awareness in retrospect. van Hooft (1998a) asserted that people can suffer even though they are not aware of it, such as those who are experiencing poverty, poor living conditions, and dangerous working conditions. This view was critiqued by Edwards who asserted that suffering must be something *felt*, that the sufferer must be aware that he or she is suffering (Edwards, 2003). As a sentient being with a sense of past and future, individuals can suffer from present threats or perceived impending threats that do not happen yet (Cassell, 2004; Murata & Morita, 2006). Empirical studies showed that patients suffered from perceived dark future ahead, fear of upcoming suffering, or worries and uncertainty about their illness in the future (Copp, 1974; Hamid et al., 2021; Morse & Johnson, 1991, cited by Daly, 1994a).

Threats to the soundness/intactness/homeostasis of the person. Cassell believed that suffering occurred when actual or perceived impending destruction threatened the intactness/integrity of the whole person, and it remained until the threat disappears or the person's integrity was restored in some other manner (Cassell, 1982, 1991b). Suffering can occur when any aspect of the person is threatened or damaged (Cassel, 1982). Therefore, it is highly related to what defines a person. A person has a lived body and mind; a person has a sense of temporality – experienced past, lived present and envisioned future; a person has a self-identity or self-concept, a sense of self or who they are; a person is fundamentally a social entity and needs relationships, group identity, and social roles; a person needs autonomy, dignity, esteem, freedom, and control over life; a person has values, desires, dreams, goals, purposes, and beliefs about self and the world (Cassel, 1982, 1991b; Charmaz, 1983; Daly, 1994a; Kahn & Steeves, 1995; Kissane, 2012; Murata & Morita, 2006; Tate & Pearlman, 2019; Trachy, 1987).

Accordingly, suffering occurs when a person experiences loss of health or pain-free status, disrupted normal functioning, broken self-identity or loss of self, loss of autonomy/dignity/self-esteem, destroyed or lost future, diminished or lost control over life, frustrated needs/desires/goals, shaken or demolished values or beliefs, loss of significant others, disrupted connectedness with others, damaged or conflicted relationships, eroded or deprived social roles, or nonacceptance or discreditation by others and the society (Bolger, 1999; Charmaz, 1983; Daly, 1994a; Daneault et al., 2004; Ellis et al., 2015; Eriksson, 2006; Morse, 2001; Murata & Morita, 2006; Paxman, 2021; Sacks, 2013; Tate & Pearlman, 2019). In essence, suffering is similar to disrupted *homeostatic equilibrium* (Daneault, 2004), an alienated *unhomelike* state of the person (Svenaeus, 2014).

Many people suffer because they are not able to be the person they used to be or they think they should be (the authentic self or the "true self") (Bolger, 1999; Charmaz, 1983; Gilot, 2008; Kissane, 2012; Morse & Carter, 1996; Sacks, 2013; Tate & Pearlman, 2019). As Charmaz elucidated, suffering occurs when "the very foundations of their self-concepts" are shaken (Charmaz, 1983, p.181). As one patient with rheumatoid arthritis in a qualitative study stated, *"I'm no longer the man I used to be, I am no longer the husband, the lover, you know, all of the aspects of my life, they are no longer there"* (Dildy, 1996, p.178). Schmitt (1981) stated that suffering ensues "when a wished-for state cannot be realized" (p.109), reflecting a discrepancy between the actual state and the ideal state of the self (Chapman, & Gavrin, 1999; Higgin, 1987; Joffe & Sandler, 1967). Since every person has desires and goals, suffering can also be caused by frustrated goals, defeated purposes, or unfulfilled needs, wishes or desires (Cassell, 1991b, 2004; Shneidman, 1993; Svenaeus, 2014; van Hooft, 2000), which may be ascribed to loss of ability due to illness, injury, or other reasons. Miceli & Castelfranchi (1997) further pointed out that the

more important the goal is, the more severe suffering the frustration can lead to. Other scholars echoed this by asserting that suffering occurs when *the most important* aspects of the person (the "core") are broken, or when *the highest* values of the person are threatened (Goldberg, 1986; Kahn & Steeves, 1995; Svenaeus, 2014). Since what is most important/highest valued for each person varies, when or to what extent a person would suffer also varies.

Considerable magnitude beyond the person's threshold to bear and cope. Both Beng et al. (2014) and Aguilera (2020) pointed out the required significant threshold for suffering to occur. This threshold was similarly referred to as a 'psychological immune system' by Papadopoulos (2007, p.302), indicating the person's capacity to respond to external threats in a resilient and resourceful way. According to Aguilera, all affective states have a valence, and an individual's overall affective state is a net valence after weighting negative and positive affective experiences. Suffering is an overall negative affective state when the negative affective valence is high enough to outweigh the positive valence and turn the overall affective state negative (Aguilera, 2020).

The threshold to bear suffering is highly individualized (Papadopoulos, 2007). Multiple risk and protective factors can influence each person's suffering threshold, such as resilience, family support, cognitive schemes, coping skills, and available support resources (Beng et al. (2014). A few researchers asserted that suffering occurred when there was exhaustion of personal and psychosocial resources for coping, and the person's regulatory system that usually worked did not lead to adaptation anymore (Chapman & Gavrin, 1993; Krikorian & Limonero, 2012; Büchi et al., 2002).

Consequences of Suffering

Consequences are outcomes that follow the occurrence of a concept (Rodgers & Knafl,

2000). Suffering can lead to positive or negative consequences. While some people gain an increased self-awareness, personal growth and a deepened relationship with others, others keep struggling, cannot get disentangled from the distress, and experience continuing, unrelieved affliction (LeMay & Wilson, 2008).

Negative. When suffering is too overwhelming and beyond the person's ability to bear it, the person may not be able to cope with it successfully, accept the reality, or find any positive meanings or gains from their experience (Dildy, 1996; Svenaeus, 2014). As a consequence, these people may experience worsened somatic symptoms and distress, undermined quality of life, consistent loss of control over life, inability to regain hope, thwarted return to normal functioning, social withdrawal, alienation to others or to self, feelings of isolation and loneness, long-lasting psychological disorders and even develop suicidal ideation (Agrimson & Taft, 2009; Best et al., 2015; Rodgers & Cowles, 1997; Bueno-Gómez, 2017; Erdner et al., 2005; Ganzini et al., 1999; Hefferon et al., 2009; Seyama & Kanda, 2008). They were stuck in their suffering and not able to move on (Best et al., 2015).

Positive. The positive change after suffering is often referred to as 'posttraumatic growth' in trauma research (Tedeschi & Calhoun, 2004) and 'adversity-activated development' in refugee research (Papadopoulos, 2007). Suffering can serve an adaptive function by signaling something wrong with the person that must be addressed, just as pain signals something not right with the body (VanderWeele, 2019). Suffering can also be a turning point that triggers changes or transformation (Arman & Rehnsfeldt, 2003; Ellis et al., 2015). For instance, patients experiencing suffering from an illness may take actions to cease risky behaviors and adopt a healthier lifestyle after realizing the value of good health that had been taken for granted before (Copp, 1974; Hefferon et al., 2009). Through the adaptation process, sufferers can also discover

inner strengths that were not previously noted, develop new coping skills and resources, enhance creative expression, and achieve a more mature and coherent psychological state (Copp, 1974; Janoff-Bulman, 2004; Schmitt, 1981; Taylor, 2012).

Suffering can help the person gain better self-insight, achieve a higher level of consciousness and functioning, and propel oneself to develop an enlightened, richer, and more complete, liberated, and authentic self; and to reach a nobler state of being (Alexander, 1973; Bolger, 1999; Das, 1971; Egnew, 2005; Ellis et al., 2015; Hefferon et al., 2009; Riscalla, 1973; Taylor, 2012). From suffering, people may find new meanings, increase appreciation for life, alter previously held beliefs and values, reappraise and reprioritize life goals, recognize new opportunities, enhance inner strength, obtain spiritual growth and greater fortitude, and achieve self-transcendence (Agrimson & Taft, 2009; Alexander, 1973; Battenfield, 1984; Dildy 1996; Ellis et al., 2015; Hefferon et al., 2009; Luboshitzky, 2008; Montoya-Juarez et al., 2013; Morse & Carter, 1996; Rodgers & Cowles, 1997; Tedeschi & Calhoun, 2004; VanderWeele, 2019).

Sufferers can also be more aware of the value of relationships and become closer to important people in life and more open to receiving help from others; existing relationships are strengthened, and new relationships are developed (Alexander, 1973; Best et al., 2015; IACOB, 2011; Janoff-Bulman, 2004; Montoya-Juarez et al., 2013; VanderWeele, 2019). They may also become more sensitive and empathic to others' suffering and more willing to help others in suffering (Dildy 1996; Morse & Carter, 1996; Svenaeus, 2014; Taylor, 2012). Some can also become more aware of social justice and initiative advocacy activities to make changes. In this case, suffering serves as a powerful social force which enhances solidarity and generates far-reaching influence on the society (Luboshitzky, 2008; Rodgers & Cowles, 1997; VanderWeele, 2019).

One explanation for the divergent consequences of suffering is *"acceptability gap"* (MacKintosh, 2013). Individuals who fail to accept their situation can be trapped in their suffering, but once they come to terms with the altered life, suffering ceases and the person will move into a positive, transformative state (Battenfield, 1984; MacKintosh, 2013; Morse, 2001; Morse & Carter, 1996; Taylor, 2012; Van Tongeren & Van Tongeren, 2021; Egnew, 2005). A second explanation is *meaning*. Suffering ceases or wanes when the sufferer finds meanings in their situation (Battenfield, 1984; Cassell, 2004; Frankl, 1963; Egnew, 2005; Park, 2010; Loeffler et al., 2018; Van Tongeren & Van Tongeren, 2021).

The attributes, antecedents and consequences of suffering are presented in **Figure 2.2**.

Definition of Suffering

Based on the analysis above, suffering is defined as *"an overall negative affective state characterized by strong and enduring negative emotions, perceived loss of control, wordlessness, loneliness, meaninglessness, and the desire to make sense of their experience. It occurs when a sentient person feels their fundamental needs or core life values/goals are threatened or failed to be fulfilled, and the intensity of the negative emotional state is beyond their threshold to bear and cope."*

Related Concepts

Related concepts are concepts that share some common characteristic with the concept of interest but do not have the exact same characteristics (Rodgers & Knafl, 2000). Identifying similar and opposite terms and comparing them with the referent concept can help resolve confusion related to this concept, enhance the clarification and understanding of this concept, and reveal relevant research repertoire (Foley & Davis, 2017; Rodgers & Cowles, 1997).

The related concepts of suffering identified in this analysis include: pain, trauma, grief, total pain, stress, distress, psychological distress, psychache/psychic pain/psychological pain, emotional pain, mental pain, spiritual pain, spiritual distress, mental anguish, psycho-existential suffering, existential distress/suffering, spiritual distress/suffering, spiritual crisis, and enduring. The most confusing distinction was between suffering and pain, which is clarified below. Other related terms are summarized in **Table 2.2.**

Pain. The International Association for the Study of Pain (IASP) defined pain as "unpleasant sensory and emotional experience associated with actual or potential tissue damage, *or described in terms of such damage*" (Raja et al., 2020). Suffering is frequently discussed together with pain, and pain is often used as a surrogate or precursor for suffering (Best et al., 2015; Rodgers & Cowles, 1997; Siler et al., 2019; Yager, 2021). Empirical evidence also confirmed significant association between suffering and pain (Fishbain et al., 2015).

However, these two concepts are different in many ways. The most intuitive difference lies in that pain has a somatic focus that always involves a physical sensory component of the body, while suffering encompasses many dimensions and does not necessarily require the existence of physical pain (Bueno-Gómez, 2017; Cassell, 1998; Fishbain et al., 2015; Williams, 1940; Yager, 2021). For example, a man may suffer from not being treated in line with his social position and dignity; a woman may suffer from unfair treatment due to poverty, gender, or race. None of these involve physical components, but they all suffer. Second, although pain often coexist with suffering, one can have pain without suffering or only with little suffering (Chapman & Gavrin, 1999; Fishbain et al., 2015; Kahn & Steeves, 1986; Yager, 2021). A study in terminally ill hospice patients revealed that patients reported suffering even when they were not having pain, and some patients who were experiencing severe pain only reported minimal suffering (Baines &

Norlander, 2000). Mothers giving birth and injured athletes who won a competition even experienced joy in pain (Leach & Kelemen, 1987).

Controllability, meaning, duration and intensity, and whether it is a threat to the integrity of a person also distinguishes suffering from pain. Pain can transfer to suffering when the person in pain feels it *out of control* (Cassell, 2004; Dildy, 1996; Löffler et al., 2018; Siler et al., 2019). Others argued that people would not experience suffering from pain until it is assigned a *meaning* or interpretation (Barrett, 1999; Kahn & Steeve, 1986; Goldberg, 1984). Moreover, suffering requires a considerable duration and intensity while pain can be transient or tiny (e.g., a quick pinprick on the finger) (Chapman & Gavrin, 1993; Edwards, 2003). Plus, suffering involves a threat to the integrity of the person or the fulfillment of intentions whereas pain mostly involves a threat to part of the body (Cassell, 2004; Reich, 1989).

Noticeably, the recent advancement of pain science has increasingly blurred the boundary between pain and suffering. Despite the tendency of treating pain as a physical experience caused by tissue damage, pain scientists have announced types of pain that is independent of nociception or noxious stimuli (e.g., neuropathic pain) (Duffee, 2021). They stated that pain is not only physical but also affects and is affected by every dimension of the whole person (psychological, social, behavioral, cultural, spiritual) (Bueno-Gómez, 2017; Eisenberger, 2015; Siler et al., 2019). Conversely, emerging evidence showed that emotional or social pain can be *sensed* as well, since these painful feelings are experienced via some of the same neural apparatuses that process physical pain (Eisenberger, 2015). However, more research is needed to fully clarify this overlap.

Opposite Concepts

Identified concepts that appear to hold opposite (or partially opposite) meanings of

suffering include hope, happiness (eudaimonia), euthymia, well-being, and healing. The definition, distinction from suffering, and an example of each opposite concept were provided in **Table 2.3**.

Discussion

To our knowledge, this analysis is the most comprehensive review of the concept *human suffering* since the seminal work by Rodgers and Cowles (1997). Although Best et al. (2015) systematically reviewed the suffering literature from 1992 to 2012 with cancer patients, the analysis was limited to negative responses to suffering. VanderWeele (2019) also analyzed the concept of suffering but did not distinguish its attributes and antecedents. The current paper comprehensively examined the suffering literature from 1940 to 2021 without a limit on type of illness, included the evolution of definitions of suffering, compared suffering with related concepts and opposite concepts, and formulated suffering as an overall negative affective state instead of a purely negative experience. It also elucidated "crisis of meaning" and "meaning making" as separate components in suffering, articulated the meaning of "threats to the intactness of the person" in suffering, and identified a new antecedent - "beyond the person's threshold to bear and cope."

Common suffering vs idiosyncratic suffering

Our analysis revealed that suffering encompasses "common suffering" and "idiosyncratic suffering." On the one hand, there are universal features that defines what a human being is, and what needs a human has, such as physical health, safety, emotions, desires and aims, social roles and interpersonal relationships, autonomy, dignity, self-esteem, and self-identify (Yager, 2021). When any of these aspects is restricted, damaged or threatened, suffering occurs (Cassel, 1982; Kioko & Meana, 2020). This is the *common* part of suffering that everyone would experience

when these events happened. On the other hand, since what is the most valued in life or what defines who they are vary from person to person (Sacks, 2013; Svenaeus, 2014; Tate & Pearlman, 2019), suffering is also *idiosyncratic.* Some events may cause suffering in some individuals but not in others (Cassell, 1991b; Schmitt, 1981). The degree of suffering can also be predicted by the hierarchy of the value that the event contains to this particular person (Miceli & Castelfranchi, 1997). This has significant implications to health care professionals and caregivers. Not only should we be aware of the fundamental needs that every patient as a holistic human being may have, but we also need to pay particular attention to patients' perspectives of their identities and what aspects or goals in life are most important to them. In this way may patients' suffering be alleviated to the greatest degree.

"Healthy suffering"

Suffering needs to be understood as an integral part of human life, not as pathology. All human beings experience illness, loss, distress, frustration, interpersonal conflicts, or other undesired occurrences at some point in life, which are not necessarily diagnosable medical problems. Scholars have pointed out the importance of not medicalizing or pathologizing suffering (Andermo et al., 2018; Hofmann, 2016; Papadopoulo, 2007; Vehling & Kissane, 2018). Fava and Guidi (2020) proposed a concept of *euthymia* vis-à-vis Aristotle's concept of *eudaimonia*. While *eudaimonia* refers to happiness that is related to self-realization and full functioning without considering the complex equilibrium of positive and negative emotions, *euthymia* denotes the optimal balance of emotions, a stable status lack of mood disturbances that meet clinical diagnostic criteria (Fava & Guidi, 2020). Linden (2020) expanded this concept by pointing out that "healthy bad mood" or "healthy suffering" should also be part of *enthymia*. In healthy suffering, people still demonstrate controllability, self-harmony, normal functioning,

mastery of environment, and positive relations with others despite the mood disturbances from hardship and predicament (Linden, 2020). From this point of view, embracing suffering as part of health instead of avoiding suffering would be a better pathway to well-being (Andermo et al., 2018).

Advanced neuroscience and implications for understanding suffering

The blurred boundary between pain and suffering due to the advancement of pain science and neuroscience warrants attention. Pain is not only physical but multidimensional that especially involves affective component (Bueno-Gómez, 2017; Eisenberger, 2015; Siler et al., 2019), and emotional/social pain may be processed via overlapped neural regions in the brain with physical pain (Eisenberger, 2015). Further advancement of neuroscience will help us gain better understanding of suffering and pain. Additionally, despite the intuition to think suffering as a conscious, subjective experience, as most scholars endorsed in the literature (Aguilera, 2020; Cassell, 1982, 2004; Edwards, 2003; Leach & Kelemen, 1987; Rodgers & Cowles, 1997; Steeves & Kahn, 1987), there were also voices arguing that suffering can be objective (Van Hooft, 1998a; Stump, 2010; Tate & Pearlman, 2019) and unconscious (Austriaco, 2016; Mayerfeld, 1992; van Hooft, 1998a). Although this argument necessitates support of empirical evidence, emergent experimental evidence favoring "unconscious emotions" (Berridge & Winkielman, 2003; Ivonin et al., 2013; Perlovsky & Schoeller, 2019) has shed light on new possibilities. If emotional states can truly be unconscious as implicit cognitions (Kihlstrom, 1999), then suffering can be unconscious as well. This understanding would indicate new direction for assessment and measurement of suffering.

Strengths and Limitations

The current study involved a systematic literature search and selection through seven

relevant databases without limitations on publication years or type of illnesses. However, the screening process was extremely difficult due to the broad range and elusive nature of this concept, high heterogeneity of articles, and lack of accurate subject terms in the databases. With a focus on patients' suffering in health and health care context, a large body of literature on theology, philosophy, literature, and sociology was excluded from the analysis. And only adults' suffering was included. Children and adolescents' suffering is significantly different that require separate devoted studies. Social and environmental suffering from poverty, war, famine, discrimination, social injustice, structural violence, regional or ethnic conflicts, genocide, and natural disasters was beyond the scope of this article and need further research. More efforts are also needed on suffering of caregivers including health care providers and family members. In addition, the identified suffering literature was dominated by Western countries, indicating underrepresented voices from Eastern cultures and developing countries. Lacking a second reviewer also predisposed the literature screening and analysis to the researcher's personal bias (Rodgers & Knafl, 2000), despite the researcher's efforts of keeping a research log, frequent self-reflections, and dedicated supervision from an advanced mentor to reduce the bias.

Conclusion

This analysis provided a conceptually and empirically grounded definition of human suffering. Suffering is an overall negative affective state where negative emotions outweigh positive ones and their intensity exceeds the person's threshold to bear. It is a consequence of disrupted basic human needs or core life goals. Rather than considering suffering as a purely negative concept, we need to notice the complexity of emotions and give more attention to the transformative power of suffering. Not to pathologize suffering but embracing it as part of life is potential to promote healing and well-being.

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Figure 2.1

Literature Searching and Selection Process

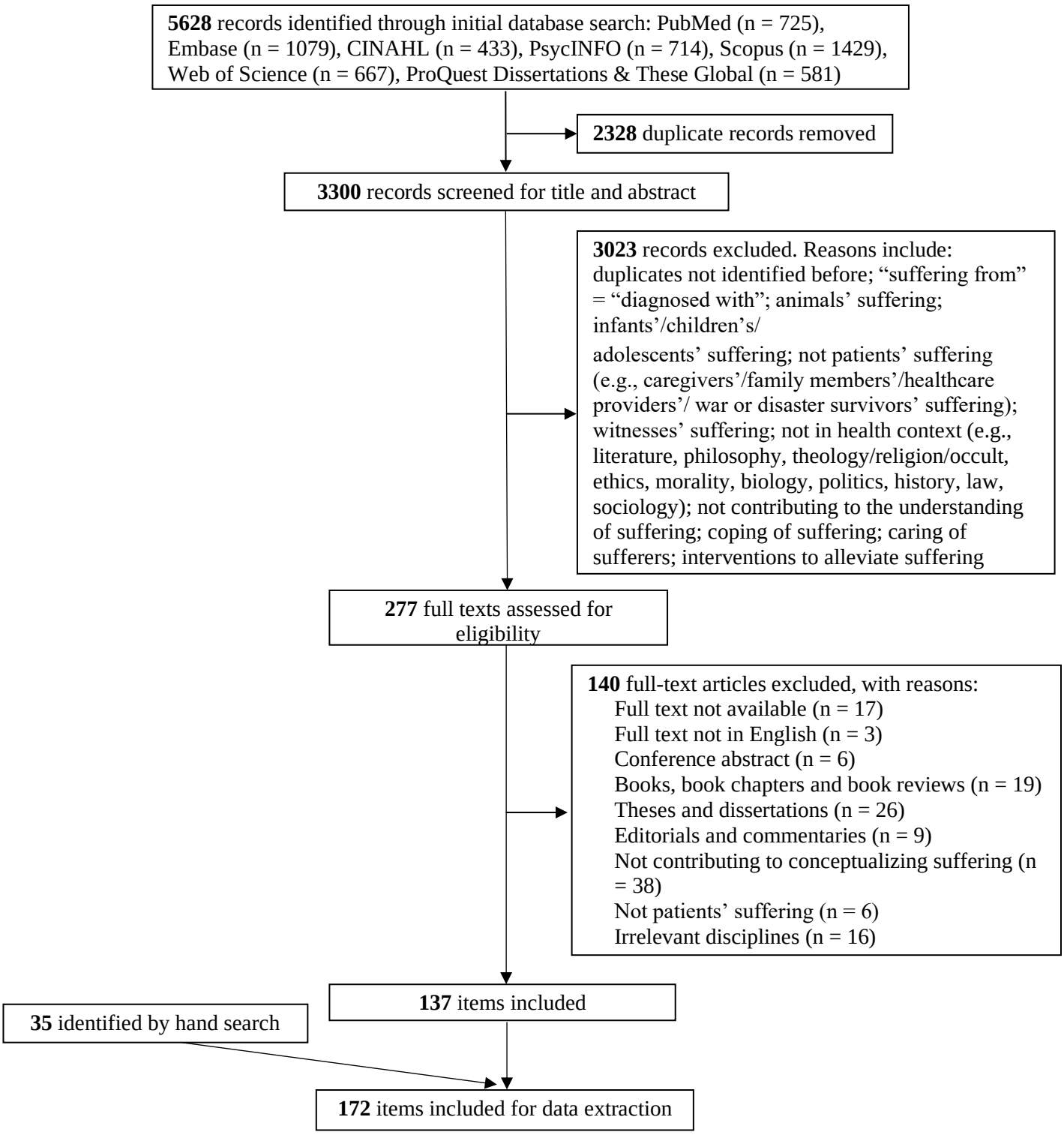

Figure 2.2

Antecedents, Attributes, and Consequences of Suffering

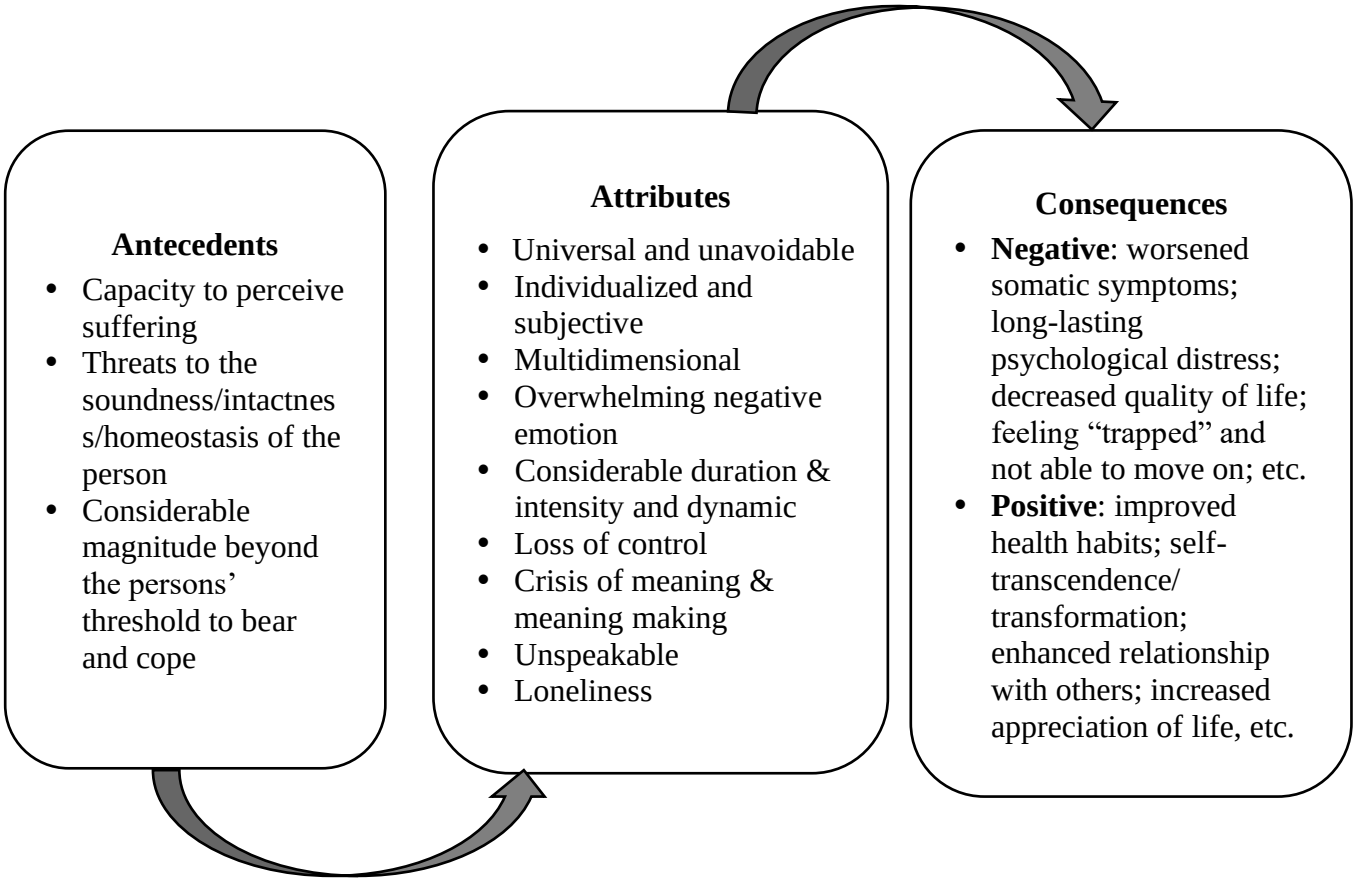

Table 2.1

Evolution of Definitions of Suffering

Author (year)	Definition	Context
Williams (1940)	"Suffering may be defined as a meaning-relevant phase of human experience - and thus in turn of human action – which is composed of two elements: an element of acute tension or strain which, *as such*, is coupled with a feeling of dissatisfaction, and an element of meaning." (p.378)	Social Psychology; USA
Copp (1974)	"Suffering is the state of anguish of one who bears pain, injury, or loss." (p.491)	Nursing; USA
Schmitt (1981)	Suffering often ensues "when a wished-for state cannot be realized." (p.109)	Psychiatry; Medicine, USA
Cassell (1982) (seminal article)	"Suffering can be defined as the state of severe distress associated with events that threaten the intactness of the person." "Suffering occurs when an impending destruction of the person is perceived; it continues until the threat of disintegration has passed or until the integrity of the person can be restored in some other manner." (p.640)	Medicine; USA Opinions on the nature of suffering and the goals of medicine as opposed to mind-body dichotomy and reductionism in medicine
Kahn & Steeves (1986)	"Suffering is experienced when some crucial aspect of one's own self, being, or existence is threatened. The meaningfulness of such threat is to the integrity of one's own experience of personal identity. … Any threat to personal integrity, whether painful or not, can invoke suffering." (p.626)	Nursing; USA Conceptual clarification and theoretical definition of human suffering
Fordyce (1988)	"*Suffering* can be defined as an affective or emotional response in the central nervous system, triggered by nociception or other aversive events, such as loss of a loved one, fear, or threat." (p.278)	Medicine; USA
Benedict (1989)	"Suffering may be defined as a negative affective state resulting from an event or situation that is perceived to be physically painful, uncomfortable, or psychologically distressing." (p.34)	Nursing; USA A cross-sectional study investigating correlates of suffering in patients with lung cancer
Kleinman, A., & Kleinman, J. (1991)	"Suffering can be defined from the historical and cross-cultural record as a universal aspect of human experience in which individuals and groups have to undergo or bear certain forms of burdens, troubles and serious wounds to the body and the spirit that can be grouped into a variety of forms." (p.280)	Medical Anthropology & Cultural Psychiatry; USA
Speck (1993)	Speck characterized suffering as pain indicating decay	NA

	and a growing sense of hopelessness (cited by Ganzini et al., 1999)	
Chapman & Gavrin (1993)	"Suffering is a complex negative affective and cognitive state characterized by perceived threat to the integrity of the self, perceived helplessness in the face of that threat, and exhaustion of psychosocial and personal resources for coping." (p. 11)	Anesthesiology; USA; Conceptualized pain and suffering in the context of cancer and palliative care
Cherny et al. (1994)	"Suffering can be described as an aversive emotional experience characterized by the perception of personal distress that is generated by adverse factors undermining the quality of life (e.g., pain, other physical symptoms, psychological symptoms, disability, existential concerns, family concerns, financial concerns, health care concerns)." (p.57)	Neurology; USA A definition of suffering in the advanced cancer patient
Daly (1994b)	"The lived experience of suffering is *paralyzing anguish with glimpses of precious possibilities emerging with entanglements of engaging-disengaging while struggling in pursuit of fortification*." (p.253)	Nursing; Australia A qualitative study using Parse' human becoming research theory & method
Morse & Carter (1996)	"Suffering is the *emotional response* to the phenomenon that has been endured or the response to an anticipated future that is lost or destroyed or to an irrevocably altered present or future because of the past event." (p.43)	Nursing; USA Compared the concepts of *enduring* and *suffering*
Rodgers & Cowles (1997)	"An 'individualized', 'subjective' and 'complex' experience characterized primarily by a person's assigning to a situation or perceived threat an intensely 'negative meaning.' This meaning involves the loss, or perceived loss of one's integrity, autonomy, and actual humanity." (p.1050)	Nursing; USA A concept analysis using Rodgers' evolutionary view
Pollock & Sands (1997)	"We defined suffering as enduring inevitable or unavoidable loss, distress, pain, or injury, whereas the meaning of the experience was the perceptions, feelings, and attitudes ascribed to the suffering experience." (p.174)	Nursing; USA A discussion about the meaning of suffering and implications for nursing
van Hooft (1998a)	"Suffering is to be understood as the frustration of the tendency towards fulfillment of various aspects of our being." (p.126) "Suffering is an objectively present condition of the person. It requires no conscious awareness on the part of the victim." (p.127)	Art and social inquiry & Medicine; Australia A discussion on suffering and the goals of medicine
Chapman & Gavrin (1999)	"Suffering, as threat or damage to the integrity of the self, entails a disparity between what one expects of one's self and what one does or is." (p.2234)	Medicine, USA Discussed pain and suffering
Reich, cited by Rushton (2001)	"An anguish experienced as a threat to our composure, our integrity, and the fulfillment of our intentions, and	Nursing, USA Discussed nursing care for

	more deeply as a frustration to the concrete meaning that we have found in our personal experience. It is the anguish over the injury or the threat of injury to the self and thus to the meaning of the self that is at the core of suffering." (p.9)	dying people
Edwards (2003)	An intuitive concept of suffering including three central components: 1) Suffering is something *felt*. 2) The felt, mental experience of suffering must be of some significant duration. 3) For a state to count as suffering it must have a fairly central place in the mental life of the subject. It must cast a pall on other activities engaged in, affect one's capacity to enjoy life during the period in which one is suffering.	Philosophy and Health Care; UK A critical assessment of the concepts of suffering proposed by Cassell and van Hooft
LeMay & Wilson (2008)	"Suffering is understood as diminished quality of life resulting from various physical, psychological, existential, familial, personal, and health-care related concerns." … "Although these definitions vary somewhat, there is a consistent message that suffering is a complex phenomenon related to an aversive emotional state, with specific causes that may arise within multiple domains, all of which threaten the integrity of the individual." (p.474)	Psychology; Canada A review of manualized interventions to address existential distress in life-threatening illness
Pilkington & Kilpatrick (2008)	"Suffering is *unbounded desolation emerging with resolute acquiescence with benevolent affiliations*." (p.228)	Nursing, Canada A qualitative study using Parse's human becoming research method
Coulehan (2009)	"Suffering is the experience of distress or disharmony caused by the loss, or threatened loss, of what we most cherish. Such losses may strip away the beliefs by which we construct a meaningful narrative of human life in general and our own in particular." (p.585)	Medical humanities; USA A discussion about suffering, poetry and medicine
Krikorian & Limonero, (2012)	"Suffering is a multidimensional and dynamic experience of severe stress that occurs when there is a significant threat to the whole person and regulatory processes (which would normally enable adaptation) are insufficient, leading to exhaustion." (p.45)	Psychology & Palliative Care; Spain A literature synthesis of the definitions and theoretical models of suffering
MacKintosh (2013)	'Suffering is a consequence of self awareness and occurs when a person's current sate fails to match a state he or she is able to accept.' – the 'acceptability gap'. (p.31)	Chapter Suffering and the 'Acceptability Gap': A Concept of Convergence from book *Making Sense of Suffering: A Collective*

		Attempt
Doucet (2014)	"Suffering is *anguishing turbulence in weaving the cherished arising with luminous shifting.* The essences anguishing turbulence, weaving the cherished, and luminous shifting articulate the concept suffering. At the theoretical level, suffering is imaging in the valuing connecting-separating of transforming." (p.100)	Nursing; Canada A concept analysis via personal experience, personal communications, literature review and engaging with different artforms based on Parse's research method
Svenaeus (2014)	"Suffering is a potentially *alienating* mood overcoming the person and engaging her in a struggle to remain at home in the face of loss of meaning and purpose in life. It involves painful experiences at different levels that are connected through the suffering-mood but are nevertheless distinguishable by being primarily about (1) my embodiment, (2) my engagements in the world together with others, and (3) my core life values." (p.413)	Medicine and Bioethics; Sweden
Best et al. (2015)	"Suffering is defined as 'an all-encompassing, dynamic, individual phenomenon characterized by the experience of alienation, helplessness, hopelessness and meaninglessness in the sufferer which is difficult for them to articulate. It is multidimensional and usually incorporates an undesirable, negative quality.'" (p.981)	Psycho-oncology; Australia A concept analysis of suffering in cancer based on a systematic review
Baumann (2016)	"The living experience of suffering is *resolve amid permeating anguish of diverse affiliations with the blissful retrieve of tranquil acquiescence*." (p.308)	Nursing; USA A qualitative study using Parse's human becoming paradigm and research method
Bueno-Gómez (2017)	Suffering is "an unpleasant or even anguishing experience which can severely affect a person on a psychophysical and even existential level" (p.8)	Philosophy & Medical Humanities; Austria A literature review on the definitions of suffering and pain
Duarte-Quilao & Strüby (2018)	"Suffering is *penetrating disheartenment amid resoluteness, as pondering with diverse alliances surfaces with lingering glimmers of destruction*." (p.350)	Nursing; Switzerland A qualitative study using Parse's human becoming paradigm
Hart (2018)	"Suffering is *anguishing desolation with varied alliances arising with envisioning anew*." (p.139)	Nursing; Canada A qualitative study using Parse' human becoming paradigm & research

		method
VanderWeele (2019)	"Suffering might be understood as the undesired experience, of considerable intensity or duration, of a negative physical or affective state." "Suffering is experienced; it involves the judgment that some aspect of one's present experience of life is negative." "Suffering cannot be assessed independent of the subject experiencing it." (p.58)	Public Health; USA A discussion of the concept of suffering drawn principally from Western philosophical and theological traditions
Kioko & Meana (2020)	Redefine suffering as "the state of cognitive awareness of, and reaction of anguish to, the loss, limitation, or distortion of one or more dimensions of personal activity. Suffering is fundamentally therefore a state of inability to fully engage in personal activity and express oneself." (p.2) "Suffering is the absence of a *thing*. And the thing that is absent or limited in the person suffering is the ability to express oneself: physically, psychologically, socially or existentially." (p.4)	Medicine; Italy A proposal for redefinition of suffering and its relief
Aguilera (2020)	"Suffering is a *conscious overall* state of *significant* net *negative* valence." (p.342)	Bioethics; USA Conceptualization of suffering from the global workspace model of human consciousness
Yager (2021)	"Suffering is the subjective experience of pervasive negative mood and psychic pain occupying most of one's mental space for a considerable length of time. Suffering is generated by sensations, feelings and reflections related to noxious experiences affecting one or more fundamental domains of human needs and motivations. These domains include biological health and disease, basic needs such as food, housing, physical safety, affiliative needs, intrapsychic and/or interpersonal issues affecting self-esteem and esteem, other goal-seeking drives, and existential aspects of life, including purpose, meaning, and transcendent perspectives." (p.5)	Psychiatry; USA A review and synthesis about suffering in patients with psychiatric disorders

Table 2.2

Related Concepts of Suffering

Concept	Definition	Distinct from suffering	Example
Stress	A non-specific biological response to a stimulus or stressor that is not necessarily harmful to the individual (Ridner, 2004, p.539)	Stress is not necessarily harmful when the stressor is manageable and even beneficial (i.e., eustress), and the person does not necessarily feel distressful (Krikorian & Limonero, 2012; Ridner, 2004). By contrast, suffering is usually aversively negative and occurs when the event is perceived as a threat/damage (Krikorian & Limonero, 2012)	Nervous but excited feelings when confronting a new challenge at work
Distress	A non-specific, biological or emotional response to a demand or stressor that is harmful to the individual (Ridner, 2004, p.539)	Distress typically refers to unpleasant subjective stress responses (negative emotions) such as anxiety and depression; it could be a transient state or a chronic condition (Matthews, 2016). By contrast, suffering is multidimensional and usually requires significant duration and intensity.	Anger at a loud noise; depressed mood after failing an exam or being criticized by others
Physical pain	An unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage (Loeser & Treede, 2008, p. 475)	Physical pain is one dimension of suffering	Nociception from skin burn
Psychological pain /psychic pain/psychache/ psychological distress/	A discomforting emotional state of intense unpleasant /negative feelings (e.g., shame, guilt, fear, sadness, hopelessness);	Psychache is intrinsically psychological, while suffering is multidimensional.	Sadness and desperate feelings after a broken relationship

emotional pain/mental pain	can be caused by disturbed mind, inner turmoil, or thwarted psychological needs (Ridner, 2004; Shneidman, 1993; Tossani, 2013)		
Soul pain *(Kearney's term for suffering)*	"The experience of an individual who has become disconnected and alienated from the deepest and most fundamental aspects of him or herself" (Kearney, 1996, p.60, cited by Coulehan, 2009)	One dimension of suffering	Unpleasant sense of alienation when a person felt he is no longer like himself after being forced to make choices against his will
Spiritual distress	A state of suffering related to the impaired ability to experience meaning in life through connectedness with self, others, world or a Superior Being (Caldeira et al., 2013, p.82)	One dimension of suffering	Distressful feelings when a person cannot find any meanings in life
Total pain	Multidimensional pain including physical, psychological, social and spiritual domains (Saunders, 1996)	Originated from the context of palliative care; shares the multidimensionality with suffering but the focus is on "pain"	The complex experience of a dying patient that includes physical pain, anxiety, depression, fear, and concern for the family who will become bereaved
Trauma	A disordered psychic or behavioral state resulting from severe mental or emotional stress or physical injury (Merriam-Webster Dictionary, 2021)	Trauma usually refers to emotional wounds nowadays (Merriam-Webster Dictionary, 2021), while suffering can refer to physical pain.	Significant fear, depression, flashbacks, and recurrent nightmares after an earthquake, hurricane, genocide, war, rape, or abuse

Enduring	An emotion-suppressed state when the individual strives to maintain control over their situation (Morse & Carter, 1996)	When the individual acknowledges what has happened, the individual moves from the emotion-suppressed state in enduring to emotion-released state in suffering (Morse & Carter, 1996)	People tried to hold themselves together in front of a family member's loss in order to function normally
Grief	The anguish experienced after significant loss, usually the death of a beloved person (APA Dictionary of Psychology, n.d.)	Suffering is a reaction to a *present* painful reality, whereas grief relates to an external loss that *no longer exists*. (Duffy, 1992; Melvin, 2004)	Sadness and persistent gloomy mood after a family member's death

Table 2.3

Opposite Concepts of Suffering

Concept	Definition	Distinction from suffering	Example
Hope	Hope is a multidimensional dynamic life force characterized by a confident yet uncertain expectation of achieving a future good. (Dufault & Martocchio, 1985, p.380)	Hope protects the hoping person by casting a positive glow on life (Dufault & Martocchio, 1985, p.380). It is more like the opposite of "despair," rather than the opposite of "suffering." And it more involves the existential dimension of suffering.	A person in dismal situation believes that the darkness will be over soon and a bright future will come.
Happiness/ *eudaimonia*	According to Aristotle, happiness is the fulfilment of inherent goals of human existence in four dimensions: to be healthy, to be just and caring, to be successful in one's endeavors, and to have a coherent theory of the world. (van Hooft, 2000)	Happiness (or *eudaimonia* according to Aristotle) is the opposite of suffering. According to the definition of happiness, suffering can be understood as frustration of inherent goals of human existence in the four dimensions. (van Hooft, 2000)	Satisfied feelings with life after self-actualization
Euthymia by Fava & Guidi	Mood stability; lack of mood disturbances; positive affects; psychological well-being (Fava & Guidi, 2020)	In euthymia only positive emotions are included, but in suffering, both positive and negative affects can coexist where the negative emotions are more dominating	Stable good mood with good psychological well-being
Euthymia by Linden	A status of wisdom, in which persons feel at ease with themselves and the world, their past, the present and the future, in good and bad times, and do not lose heart and courage in the face of adversities and	A status of well-being, a balance of good mood and bad mood; whereas in suffering the negative emotions outweigh the positive ones	A status of homeostatic equilibrium in emotions where the person feels inner peace, satisfied, and vigorous

	hardship. (Linden, 2020)		
Well-being	"A state of happiness and contentment, with low levels of distress, overall good physical and mental health and outlook, or good quality of life" (APA Dictionary of Psychology, n.d.)	A sound life status with no significant deficiency as in suffering	Good feelings of a person who is healthy, happy, self-satisfied, has stable financial sources and good relationships with others
Healing	Healing is overcoming an undesirable condition to restore wholeness and integrity among all dimensions of one's being. A person can experience healing even not cured. (Coward & Reed, 1996)	Healing is the transcendence of suffering. (Egnew, 2005)	A person with depression managed to reconcile with himself, transcend his suffering, and begin a new life with a reconstructed new identity.

Chapter 3: Construction of a Measurement Tool of Common Dyadic Coping: The Importance of Open Communication

Abstract

Objectives: An extensive literature demonstrates the importance of couples' jointly coping to manage the impact of breast cancer on the couple. Despite its importance, measures of couples' coping behavior have substantially lagged behind need. The purpose of the current study is to generate a self-report valid and reliable measure of couples' coping with breast cancer.

Methods: Baseline data of 343 women and 343 spouses who participated in a randomized clinical trial testing the efficacy of a communication-focused psycho-educational intervention were used for analysis. Women were diagnosed with early-stage breast cancer in the past eight months; couples were married or in an intimate relationship for at least six months, could read and write English, and lived within 100 miles of the study center. Measurement construction proceeded through three phases: an expert panel to confirm the conceptual fit of items with a definition of common dyadic coping; exploratory factor analysis to identify the factorial structure of the measure; and confirmatory factor analysis to examine goodness of fit of the identified model. Items were extracted from the Mutuality and Interpersonal Sensitivity Scale (MIS) used in the clinical trial.

Results: This study generated a 12-item, 4-factor measure of common dyadic coping with a particular focus on open communication (CDC-C). Expert panel selected 16 items as indicators of common dyadic coping with an interrater reliability of 0.75. Exploratory and confirmatory factor analysis established a 12-item, 4-factor measurement model with satisfactory model fit (for women: $\chi^2[39] = 58.406$, robust CFI = 0.984, robust RMSEA = 0.048, SRMR = 0.042; for spouses: $\chi^2[39] = 65.152$, robust CFI = 0.981, robust RMSEA = 0.045, SRMR = 0.043). The four factors are: *Keeping the communication open with each other about breast cancer, Sharing a positive outlook on breast cancer, Avoiding discussion of negative thoughts and feelings about*

breast cancer, and *Spending sufficient time together talking about breast cancer.* Reliability indicated by McDonald's omega ranged from 0.76 to 0.87 for women and 0.70 to 0.83 for spouses.

Conclusions: Common dyadic coping is optimally measured in four distinct dimensions mainly regarding communication. This new measure is potential to be used in clinical practice and future research to assess couple's joint coping efforts especially through communication.

Key words: common dyadic coping, measurement tool, factor analysis, open communication

Introduction

Growing evidence showed that couples often responded as a system instead of as individuals in the face of breast cancer (Hagedoorn, Sanderman, Bolks, Tuinstra, & Coyne, 2008). They appraised cancer-related stress as a unit, communicate strategies and emotions, and respond to the stress together (Kayser et al., 2007).

In the 1990s, considering the reciprocal and dynamic interplay between partners in close relationships, Swiss psychologist Bodenmann adapted Lazarus and Folkman (1984)' individual-based transactional theory of stress and proposed the Systematic-Transactional Theory and the concepts of "dyadic stress" and "dyadic coping," to indicate the stress that affects both partners and the dyad's joint efforts in stress coping (Bodenmann, 1995, 1997). The emergence of dyadic coping suggested a paradigm shift from an individual to an interpersonal perspective on stress and coping (Berg & Upchurch, 2007; Rentscher, 2019).

Depending on how the two partners are involved in the coping process, Bodenmann (1997, 2005) categorized dyadic coping into *supportive dyadic coping*, where one partner takes efforts to support the other partner; *delegated dyadic coping*, where one partner takes over some tasks or duties of the other partner to reduce their stress; *common dyadic coping*, where both partners are engaged symmetrically or complementarily to deal with a dyad-relevant issue; and negative forms including *hostile, ambivalent, and superficial dyadic coping*.

Common dyadic coping (CDC), the joint effort of a couple to cope with shared stressor, was also referred to as *communal coping* (Lyons et al.,1998) and *collaborative coping* in the Development-Contextual Coping Model (Berg & Upchurch, 2007). There are three common characteristics of this type of coping: the stressor is regarded as a "we" problem instead of a "I" or "you" problem; couples communicate and share an appraisal about the situation; and conjoint

actions are taken to deal with the stressful situation together. The most commonly used measurement tool for common dyadic coping in the literature is a five-item subscale in the Dyadic Coping Questionnaire (FDCT-N; Bodenmann, 2000) and the further developed Dyadic Coping Inventory (DCI; Bodenmann, 2008). Validation studies in various countries have identified the factorial structure of this subscale as either including two domains (problem-focused CDC, e.g., "We try to cope with the problem together and search for ascertained solutions," and emotion-focused CDC, e.g., "We are affectionate to each other, make love and try that way to cope with stress") or three domains (problem-focused, seeking closeness, and relaxation). Other measures for assessing dyadic coping include the Relationship-Focused Coping Scale (RFCS; Coyne & Smith, 1991), Collaborative Coping Questionnaire (CCQ; Berg, Johnson, Meegan, & Strough, 2003), and the self-report measure of communal coping (Rohrbaugh et al., 2008; Helgeson et al., 2018).

In these models and scales, however, the importance of the couple's mutual communication is underestimated. Existing items assessing communication asked *general* questions (e.g., in the Collaborative Coping Questionnaire, the extent to which the couple shared feelings and concerns about the disease) (Berg et al., 2003) or formulated the questions from an individual perspective not as "we" statements (e.g., "I tell my partner openly how I feel" in DCI) (Bodenmann, 2008). The *specific* elements of communication were not assessed such as its pattern, type, time, and quality. Considering the importance of open communication in relationship functioning (Langer et al., 2018; Manne et al, 2006), what was still needed was a measurement tool that assessed the specific elements of couples' communication in dyadic coping in which the couple is perceived as a unit.

Our study aimed to construct such a measure of common dyadic coping (CDC). Based on Bodenmann's definition of CDC (1997, 2005) and Yang's definition of coping (2018), we defined CDC as *"the conjoint effort of both partners in the couple to deal with breast cancer related stress by means of stress communication, sharing of feelings and concerns, relaxing together, joint problem-solving, joint cognitive appraisal/restructuring, use of available supports and resources, or other purposeful actions."*

Methods

Design

This study involved a secondary analysis of baseline data obtained from a recently completed randomized clinical trial, Helping Her Heal (HHH) whose goal was to test the efficacy of a five-session psycho-educational intervention targeting marital communication and interpersonal support for couples facing newly diagnosed breast cancer (Lewis et al., 2019). Data analyzed in the current study were obtained prior to randomization. Human Subjects approval was obtained from University of Washington Institutional Review Board (IRB ID: STUDY00014873).

Sample

Baseline data included 343 women with breast cancer and their 343 spouse caregivers. Women were eligible if they were diagnosed within the past eight months with early-stage breast cancer [stage 0-III; in situ regional disease]; married or in an intimate relationship with her spouse caregiver; could read and write English; and lived within 100 miles of the study center. Spouses were eligible if they were married or cohabited with the diagnosed woman for six months or longer, have English as one of their languages of choice, and resided in the same residence (Lewis et al., 2019).

Sample Size

Two methods were considered in estimating the required sample size for factor analysis. A sample size of 100 is considered poor, 200 is fair, 300 is good, 500 is very good, and 1000 or greater is excellent (Comrey et al., 1973, cited by Kyriazos, 2018). Considering the ratio of the required participants to the number of indicator variables, 5-10 participants per item is recommended (Tinsley & Tinsley, 1987, cited by Kyriazos, 2018). In the current study, 343 women with breast cancer and 343 spouse caregivers completed the study measures, and missing data for both groups were less than 5%. Considering the number of selected items to be examined, the sample size was sufficient.

Measure

The Mutuality and Interpersonal Sensitivity Scale (MIS) from the HHH study (Lewis et al., 2019) was the questionnaire from which items were extracted to measure CDC. MIS is a self-report questionnaire used to measure the ways that the couple communicated with each other about the breast cancer. It contains 32 items on a 5-point ordinal scale (1 = "Never true", 2 = "Seldom true", 3 = "Sometimes true", 4 = "Occasionally true", and 5 = "Always true"). It contains two subscales: Open Communication (e.g., "We spend a lot of time talking about how things are going with the breast cancer) and Expressing Sad Feelings (e.g., "We don't talk together about the sadness I feel about the breast cancer."). Total scores could range from 32 to 160 and a higher score indicates a higher quality of marital communication about breast cancer. In the HHH study, the internal consistency for the two subscales was 0.92 and 0.86 for women, and 0.88 and 0.82 for spouses, respectively (Lewis et al., 2019).

Expert Panel Review

An expert panel consisting of three members who had expertise in psychometrics or scale

development and were familiar with the coping research area was invited to review the 32 MIS items for content-relevance as a measure of CDC. The experts were provided with a review sheet with the definition of CDC, a random list of all MIS items, and instructions on how to score the degree of relevance of the item to the concept of CDC (see the Appendices for the Expert Review Sheet). Experts were asked to decide the relevance or non-relevance of each item and to assign the item from the following three choices: "Yes, relevant," No, not Relevant," or "Maybe" for each item and provide specific reasons for each decision. The Fleiss Kappa coefficient was used to assess the inter-rater agreement (Nichols, Wisner, Cripe, & Gulabchand, 2010). A Kappa value of 0.40-0.60 indicates moderate agreement, 0.61-0.80 indicates substantial agreement, and 0.81-1.00 indicates almost perfect agreement (Nichols et al., 2010). The review was conducted in iterative rounds until a satisfactory agreement level was achieved. And once achieved, a consensus meeting was held among all experts and the researcher to address the discrepancy and determine which items to be included in the item pool for factor analysis.

Statistical Analysis

Descriptive statistics, including mean, standard deviation, skewness, kurtosis, histograms and ggplots were first used to describe the data distribution and identify any missing data or outliers. Five cases (1.4%) were detected with missing values for the women's and spouses' data separately. Schafer (1999) recommended that missing values of 5% or less is inconsequential if the data are missing at random. We believed our missing data were missing at random, so listwise deletion was used for the analyses. Histograms, gg-plot, and Mardia's kurtosis statistic were used to examine the normality of the data. The intercorrelation of items was also examined. Factor analysis was conducted separately for the diagnosed women and spouses to examine the factorial structure of the scale.

Exploratory factor analysis (EFA) was first conducted to identify the underlying factor structure (Beaujean, 2014; Martin & Savage-McGlynn, 2013). The Eigenvalue >1 rule, Scree plot, and Parallel Analysis (Çokluk & Koçak, 2016) were used to determine the number of factors. Since we believed many MIS items were intercorrelated, oblique rotation method was used to allow the factors to be correlated (Kline, 2016). Items with high factor loadings (> 0.5) on one factor and low crossloadings (< 0.4) were considered to retain (Ho, Chan, & Ho, 2004). Items with low factor loadings and high crossloadings were considered for removal (Costello & Osborne, 2005; Martin & Savage-McGlynn, 2013).

Confirmatory factor analysis (CFA) was then conducted to examine the model fit of the structures that were resulted from the EFA (Beaujean, 2014; Martin & Savage-McGlynn, 2013). Chi-square statistics, p-value, and three model fit indices were used to assess the goodness-of-fit of the model: comparative fit index (CFI), root mean square error of approximation (RMSEA), and standardized root mean square residual (SRMR). The model is considered to have a good fit if p-value > 0.05, or CFI > 0.95, RMSEA < 0.05, and SRMR < 0.08 (Hu & Bentler, 1999). Model selection indexes including Akaike's information criterion (AIC) and Bayesian information criterion (BIC) were also used to inform the model selection (Burnham & Anderson, 2004). A lower AIC or BIC value indicates a better fit of the model (Kline, 2016). Model modification was made based on residual analysis and modification indices analysis until the model reached satisfactory fitness. The sample of women and spouses were respectively split into two random subsamples for factorial analysis: one third of the sample (n= 113) was used for EFA and the other two thirds (n = 225) were used for CFA.

The internal consistency reliability of the measurement model was assessed using McDonald's omega because congeneric models (lifting restrictions on the constancy of factor

loadings and item errors) were applied. When the tau-equivalence assumption (assuming constant factor loadings) was violated, McDonald's omega is a more accurate estimator than Cronbach's alpha because the latter would underestimate the internal consistency (Dunn, Baguley, & Brunsden, 2014; Hayes & Coutts, 2020). A McDonald's omega value over 0.7 is believed to indicate acceptable internal consistency reliability (Nunnally & Bernstein, 1994). Data analyses were conducted in R version 4.2.0 and IBM SPSS 28.0.0.0.

Results

Demographic of Study Participants

After removing the five cases with missing values, 338 cases remained for the diagnosed women and the spouses separately for factor analysis. Couples were married for 23 years on average (ranged from 0~56 years). The women's age ranged from 29 to 81 years old, with an average of 53.3 (SD = 11.4). The spouses were all male, and aged between 26 to 90, with an average of 55.0 (SD = 12.1). Most couples were White (> 80%), had college education or above (> 70%), and had annual household income of $75,000 and above (> 70%). The majority of the spouses worked full time (64.5%), while only a small portion of women worked full time (26.3%) or part time (18.9%). The average time since the diagnosis were 3.3 months (SD = 1.3). Most women (84.9%) had received surgery for breast cancer. See **Table 3.1** for details.

Results from Expert Panel Review

In the first round of review, the Kappa coefficient was 0.233, indicating poor inter-rater agreement level (Nichols et al., 2010). Fifteen items were rated as "relevant" by all experts; one item was rated consistently as "not relevant;" 16 items were rated with inconsistency. Discrepancy mainly lied in whether items in the four areas below were relevant to measure CDC:

1) couple's shared beliefs (e.g., "Talking together about things other than the breast cancer makes things better"); 2) couple's shared thoughts about how to deal with breast cancer (e.g., "We think that talking about the breast cancer only makes things worse"); 3) couples' descriptions of their current status (e.g., "We are comfortable sharing feelings about the breast cancer with each other"); and 4) couples' communication/talking about breast cancer (e.g., "We spend a lot of time talking about how things are going with the breast cancer").

These discrepancies were resolved by revisiting the definition of CDC in the literature, studying items of other coping/dyadic coping scales, and discussing each expert's thoughts in a meeting. The panel finally decided that all non-action beliefs, thoughts, descriptions of status were not indicators of CDC, but communication/talking about breast cancer was a type of CDC. With this consensus, the second round of review was conducted. Kappa coefficient reached 0.75 this time, suggesting satisfactory inter-rater agreement (Nichols et al., 2010). Fifteen items were rated as "relevant" by all; 11 items were rated consistently as "not relevant;" six items were rated with inconsistency. A final consensus meeting was then held to make final decisions on which items to retain. Sixteen items were determined to be relevant to measure CDC and retained for examination in factor analysis.

Descriptive Analysis of Selected Relevant Items

The mean score and standard deviation of the 16 selected items from expert panel review are summarized in **Table 3.2**. Items 12, 21, 23, 30, and 31 were reverse scored. The Mardia's kurtosis test rejected the multivariate normality ($p < .05$) for both groups. All individual item scores were also not normally distributed; many were left skewed. The inter-item correlations indicated by Spearman's correlation coefficients are presented in **Tables 3.3 and 3.4**. The item correlations were lower in magnitude for spouses than were the item correlations for the

diagnosed women.

Exploratory Factor Analysis for the Selected Items

For women's data, the eigenvalue > 1 rule, scree plot, and parallel analysis consistently determined three factors. However, for spouses' data, the number of factors was determined to be two or four. To explore which structure fit both women's and spouses' data better, we examined the two-, three- and four-factor models separately in EFA using oblimin rotation and principal axis factor extraction method. Analyses in women's data generated clear factorial structures. However, analyses in spouse' data did not. Therefore, spouses' data were randomly split again into 1/3 and 2/3 subsamples where the 1/3 was used to run a second EFA. The results from the first and second EFA were significantly heterogeneous, causing us to re-run EFA using all spouses' data to see if the factorial structure became clearer.

The amount of explained variance explained by competing two-, three-, and four-factor model was 51.6%, 59.3%, and 64.4% separately for the women's data, and 37.0%~39.2%, 42.5%~44.7%, and 47.1%~48.8% for the spouses' data. Integrating the EFA results in the two groups together, items to be examined in CFA were selected based on their factor loadings, item reliability, theoretical considerations of the items' meaning, and the relevance of items loaded on the same factor.

Confirmatory Factor Analysis of Two-, Three- and Four-Factor Models

The competing two-, three-, and four-factor models resulted from EFA were tested using CFA with maximum likelihood estimation. Since the multivariate normality for both groups was rejected, Robust Maximum Likelihood Estimation method was used for all analyses. The 2/3 subsample of women' data from the first random spit and all spouses' data were used.

The initial models did not fit well for both women and spouses' data. Model modification

was carried out based on analyses of residuals' correlation and model indices, by adding covariance paths between residuals of items which had theoretical interpretability. Modification was continued in the two groups simultaneously until the same model achieved a satisfactory model fit for both women's and spouses' data. The final model structures of the two-, three-, and four-factor model are shown in **Figure 3.1 - Figure 3.6**. **Table 3.5** summarizes the model fit indices of the three competing models for spouses' and women's data.

The two-factor model and the four-factor model had comparable model fit; both had better fit indices than the three-factor model. However, the four-factor model distinguished between four aspects of couples' communication and coping behavior which provided greater theoretical significance and interpretability than did the two-factor model. Therefore, the four-factor model was accepted to be the best fit model for measuring CDC.

Dimensions and Internal Consistency Reliability of the Four-Factor Model

The accepted four-factor model contained 12 items. Each dimension was labeled based on the clustered meanings of the items within the same factor. Since the internal consistency coefficient requires unidimensionality of the scale (Dunn, Baguley, & Brunsden, 2014), McDonald's omega for each subscale was calculated. The *Keeping the communication open with each other about breast cancer* subscale contained four items; the McDonald's omega value was 0.87 for women and 0.78 for spouses. The *Sharing a positive outlook on breast cancer* dimension included two items. The McDonald's omega could not be estimated since there were fewer than three items in the subscale. The *Avoiding discussion of negative thoughts and feelings about breast cancer* subscale had three items. The McDonald's omega value was 0.76 for women and 0.70 for spouses. The last subscale, *Spending sufficient time together talking about breast cancer,* included three items; the McDonald's omega value was 0.85 for women and 0.83

for spouses. The internal consistency of each subscale was considered acceptable at this stage of the measurement's development. See **Table 3.6** for the factor loadings of items in each dimension.

Discussion

This study generated a 12-item, 4-factor measure of common dyadic coping with a particular focus on open communication (CDC-C) in the context of breast cancer. The four factors include: *keeping the communication open with each other about breast cancer*, *sharing a positive outlook on breast cancer*, *avoiding discussion of negative thoughts and feelings*, and *spending sufficient time together talking about breast cancer*. These factors call out the uniqueness of four aspects of the couples' communicating about the breast cancer: the importance of the couple expressing and exchanging concerns about breast cancer with no hiding, facing difficult conversations about breast cancer with no holding back, sharing their views about the breast cancer, and the role of the amount of time talking together about the breast cancer.

Many studies demonstrated the critical benefits of *open communication* and the harm of hiding, denying, concealing concerns and feelings, communication avoidance and withdrawal on relationship closeness, marital satisfaction, and psychological adjustment of patients with breast cancer and their partners (Langer et al., 2018; Manne et al, 2006; Valente et al., 2021; Yu & Sherman, 2015). However, previous dyadic coping scales did not assess open communication thoroughly. For instance, DCI only included two questions regarding open expression of feelings between partners from the individual person's perspective ("I tell my partner openly how I feel" and "My partner tells me openly how he/she feels") and one item assessed the couple's problem-solving focused discussion ("We engage in a serious discussion about the problem and think

through what has to be done"). None of the scales assessed the exchange of cancer-related concerns and feelings in "*we*" statements.

The factor *avoiding discussion of negative thoughts and feelings* was similarly assessed in RFCS as protective buffering (e.g., hiding concerns, denying worries) (Coyne & Smith, 1991), in Communication Patterns Questionnaire as 'mutual avoidance of discussion' (Christensen & Heavey, 1990) and in other scales assessing the extent to which members of the dyad held back from discussing cancer-related issues or expressing concerns and feelings with the partner (Donovan-Kicken & Caughlin, 2010; Porter et al., 2005). As with the other questionnaires, these scales did not use "*we*" statements that reflected the dyad as a unit. According to Rentscher (2019), spouse *we*-talk was associated with relationship quality, less patients' psychological distress and improved patients' physical symptoms and general health functioning. This indicates that using "*we*" statements in the dyadic coping measures could be potentially beneficial.

Shared positive outlook was similarly assessed in the DCI with the item "We help one another to put the problem in perspective and see it in a new light" (Bodenmann, 2008). The final factor, *spending sufficient time together talking about breast cancer,* identifies a unique aspect of couple's dyadic coping in our measure that was not documented in prior research. It reflects a *time* element. This new element raises a host of important questions. Does the amount of time the couple spends on talking about breast cancer matter? Does the couple's mutual communication require a minimum amount of time to be adaptive? Do couples spending more time talking about breast cancer-related concerns have better adjustment, relationship satisfaction, and better health outcomes? These questions require exploration in future research. Considering these gaps, our 12-item measure of CDC provides an initial measure for potential future use.

Despite the overlaps of components in our scale and other existing scales measuring dyadic coping or communication, our study, for the first time, established a four-dimension communication-focused measure for the construct of common dyadic coping. However, we also had limitation. First, as a secondary analysis, the identified domains of CDC were limited by the existing pool of items that were available to us in the battery of measures obtained at baseline in HHH. Other domains related to dyadic coping were not available to be included, e.g., joint stress appraisal, joint information seeking, joint problem-solving, empathic responding, affectionate support, and communal relaxation (Bodenmann, 2005; Falconier, Jackson, Hilpert, & Bodenmann, 2015). Future research on common dyadic coping should include additional items than those tested in the current study.

Second, various dyadic coping models suggested that the process of CDC comprises two stages: 1) "*we*-appraisal", where the couple appraise to which degree they perceive the stressor as a "*we*-problem" and jointly evaluate the severity of the stressor and their communal capacity and resources to cope with it; 2) "*we*-action", where the couple engage in collaborative coping to manage the stressor (Berg & Upchurch, 2007; Bodenmann, 1995; Kayser & Revenson, 2016; Lyons et al., 1998). Our factor analysis did not identify the "*we*-appraisal" domain, which is also missing in most other dyadic coping measures. The only existing measure that assessed the couple's shared appraisal simply asked to what extent the couple viewed the illness as "our problem" instead of or their own problem (Rohrbaugh et al., 2008). However, the second component of couple's joint appraisal- how they perceive the stressor and their capacity to cope with it- was absent. Future studies should include the "*we*-appraisal" elements in dyadic coping measurement.

Third, our study sample was predominately White, heterosexual, middle-aged, well-

educated couples in the upper-middle class in the United States. Many of their responses to the self-report items were negatively skewed, indicating open and frequent communication, mutual support, and positive outlook towards breast cancer. This is possibly affected by the tendency of favoring openness, explicit verbal communication, and actively seeking social support for coping with stress in American culture (Falconier, Randall, & Bodenmann, 2016; Goldsmith et al., 2007). Further research is needed to assess couple's communication and coping with other populations and in other countries.

Conclusion

Our study identified a four-factor measurement model for common dyadic coping. Study findings emphasized the importance of open and fully disclosing communication in couples dealing with breast cancer together. Future studies should add additional items to the current measure of common dyadic coping, including the couple's joint appraisal. Future research would also benefit from assessing the predictive validity of this new scale in predicting couples' relationship satisfaction, mental health, stress management, and adjustment to breast cancer.

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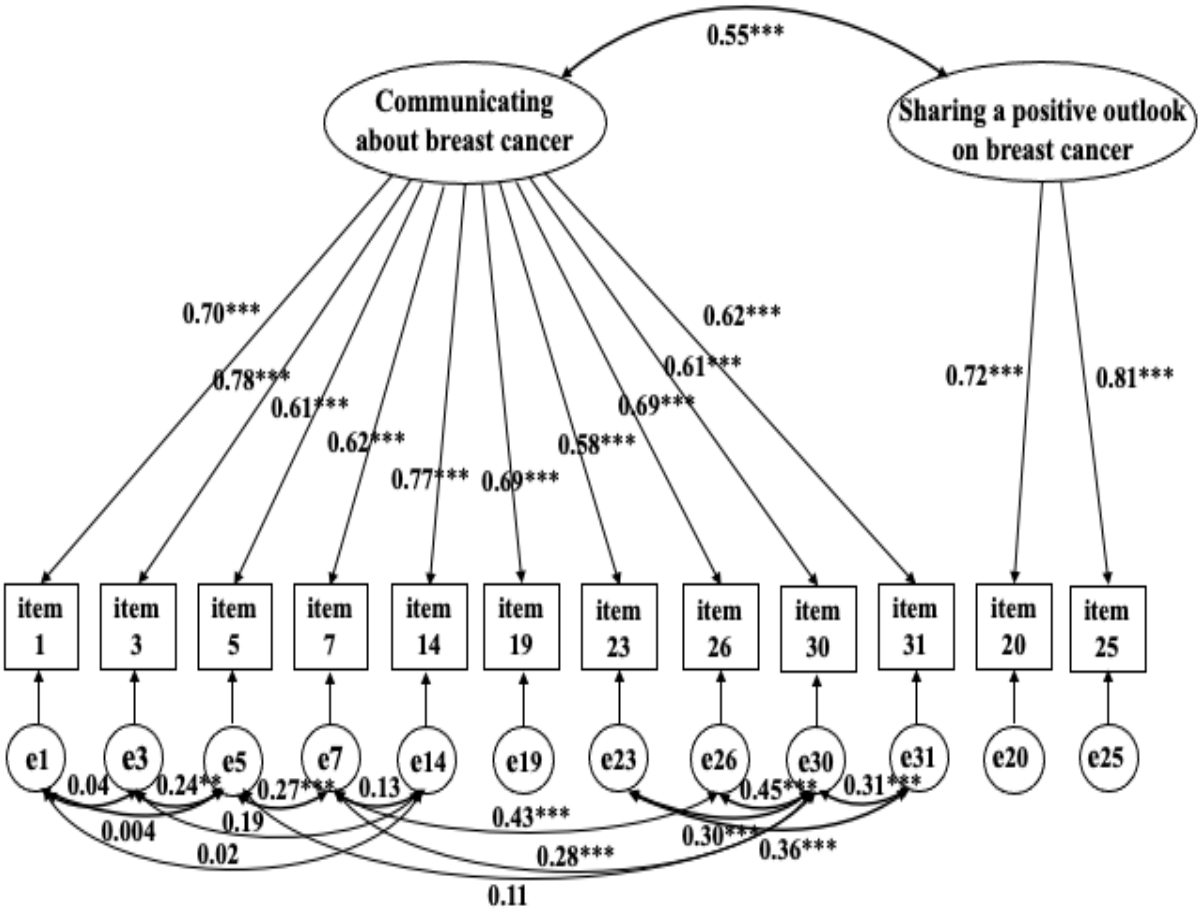
Figure 3.1

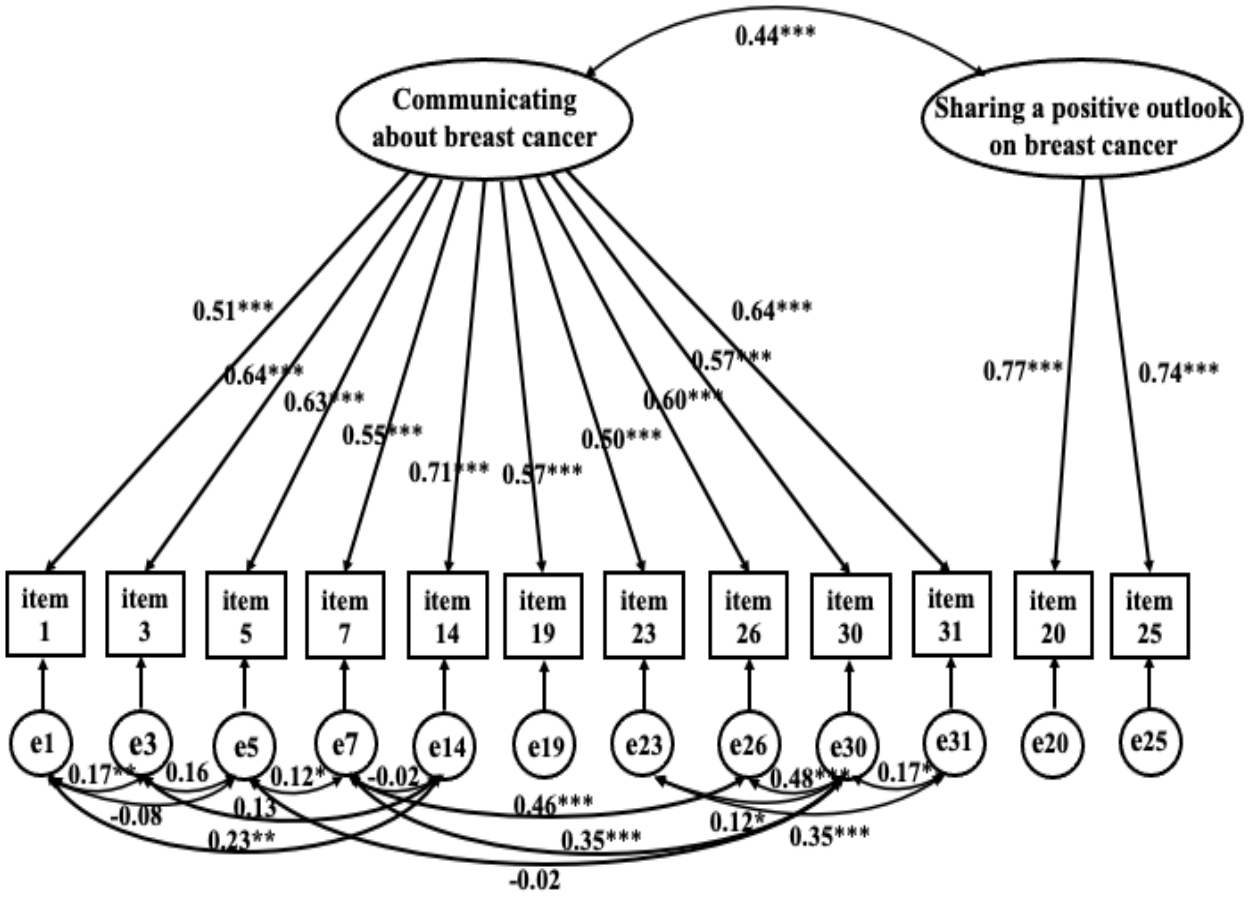
Two-Factor Model in Diagnosed Women



Note. The number on the paths showed the standardized factor loading or covariance between factors or between residuals. Model fit indices: Chi-square = 59.346, df = 39, p-value = 0.019, robust CFI= 0.983, robust RMSEA = 0.049, SRMR = 0.044. AIC = 6428.014. BIC = 6561.242. *p < .05, **p < .01, ***p < .001.

Figure 3.2

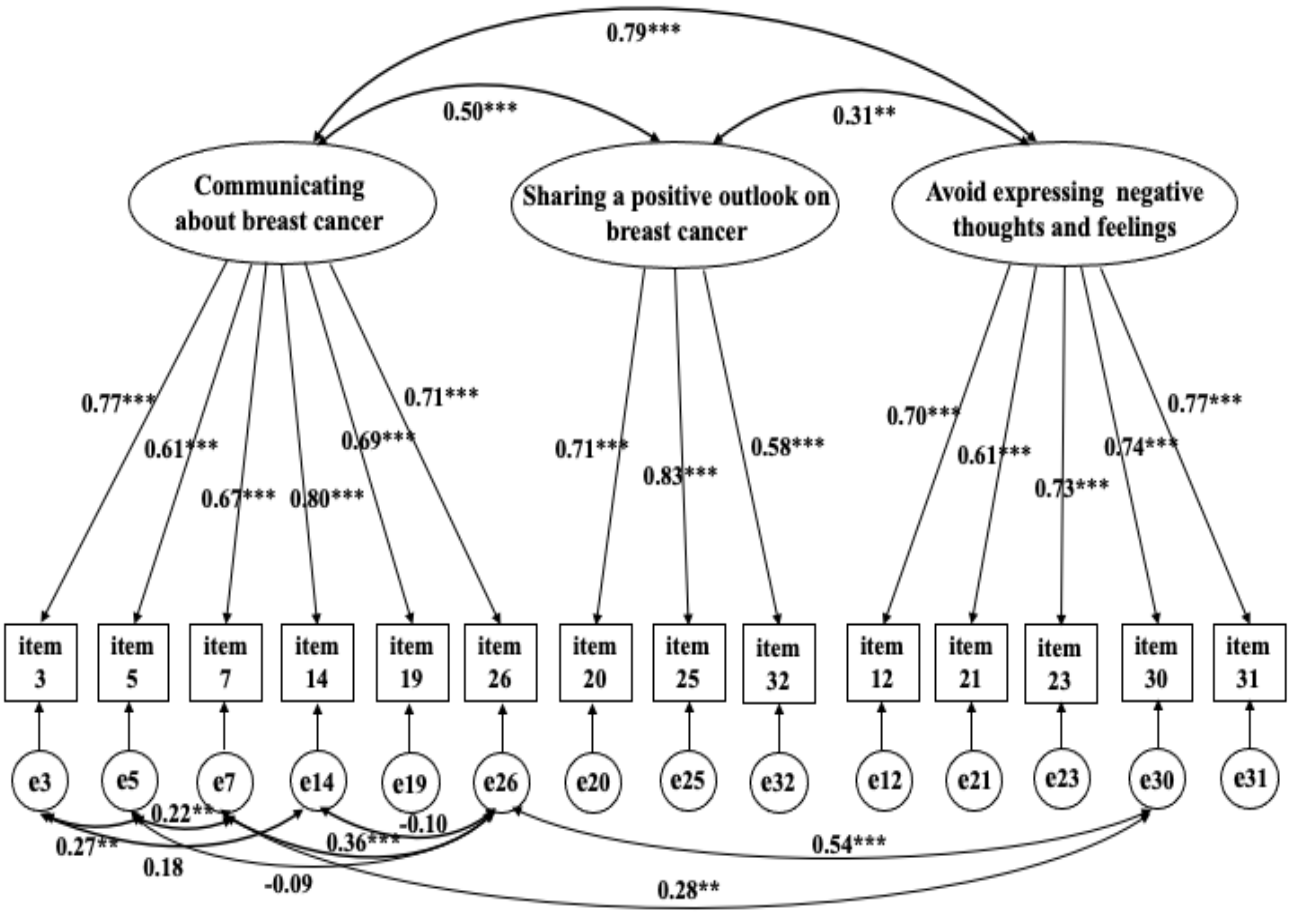
Two-Factor Model in Spouses



Note. The number on the paths showed the standardized factor loading or covariance between factors or between residuals. Model fit indices: Chi-square = 72.488, df = 39, p-value = 0.001, robust CFI= 0.976, robust RMSEA = 0.050, SRMR = 0.042. AIC = 9262.162. BIC = 9411.260. *p < .05, **p < .01, ***p < .001.

Figure 3.3

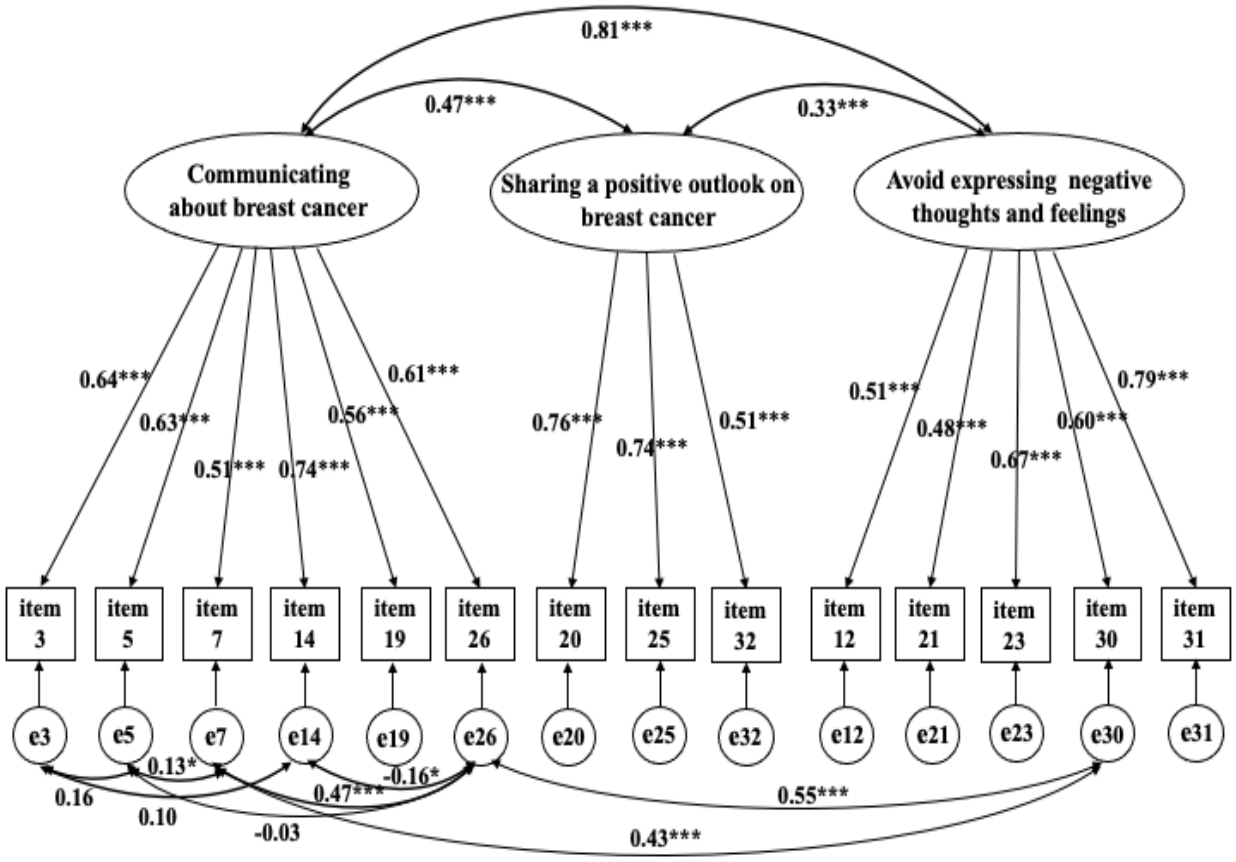
Three-Factor Model in Diagnosed Women



Note. The number on the paths showed the standardized factor loading or covariance between factors or between residuals. Model fit indices: Chi-square = 93.432, df = 66, p-value = 0.015, robust CFI= 0.979, robust RMSEA = 0.045, SRMR = 0.048. AIC = 7844.863, BIC = 7978.091. *p < .05, **p < .01, ***p < .001.

Figure 3.4

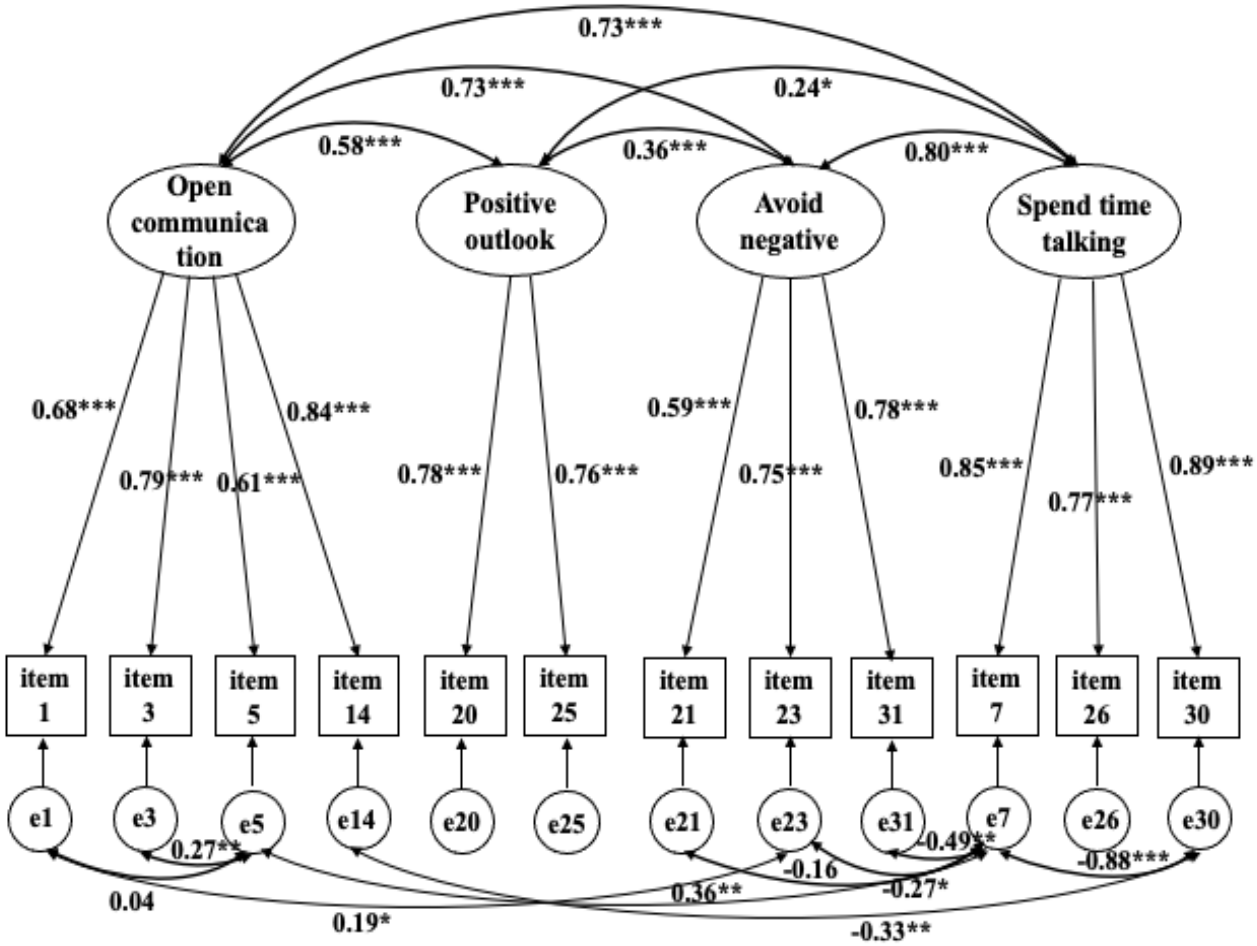
Three-Factor Model in Spouses



Note. The number on the paths showed the standardized factor loading or covariance between factors or between residuals. Model fit indices: Chi-square = 116.741, df = 66, p-value = 0.000, robust CFI= 0.964, robust RMSEA = 0.049, SRMR = 0.054. AIC = 11558.067, BIC = 11707.165. *$p < .05$, **$p < .01$, ***$p < .001$.

Figure 3.5

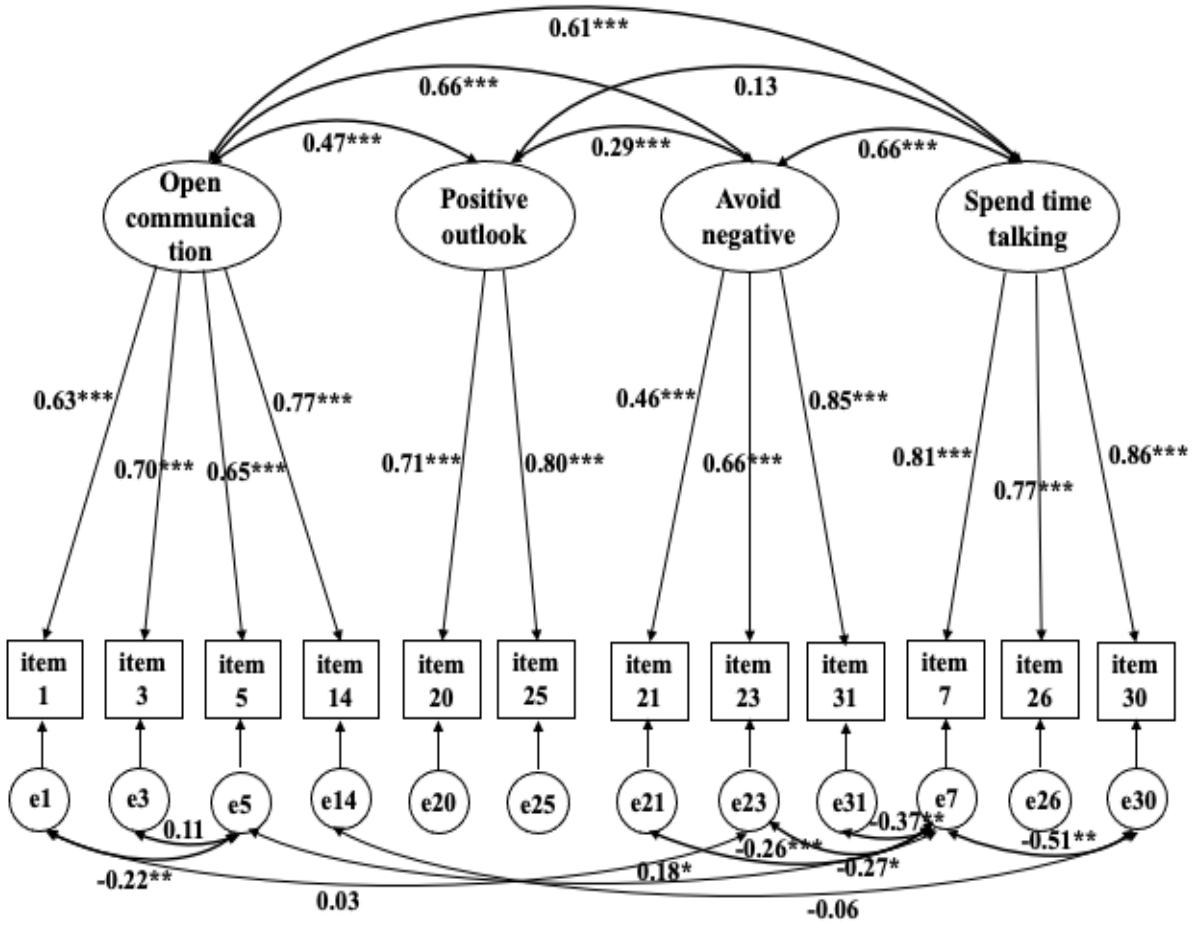
Four-Factor Model in Diagnosed Women



Note. The number on the paths showed the standardized factor loading or covariance between factors or between residuals. Model fit indices: Chi-square = 58.406, df = 39, p-value = 0.024, robust CFI= 0.984, robust RMSEA = 0.048, SRMR = 0.042. AIC = 6444.229, BIC = 6577.456. *p < .05, **p < .01, ***p < .001.

Figure 3.6

Four-Factor Model in Spouses



Note. The number on the paths showed the standardized factor loading or covariance between factors or between residuals. Model fit indices: Chi-square = 65.152, df = 39, p-value = 0.005, robust CFI= 0.981, robust RMSEA = 0.045, SRMR = 0.043. AIC = 9306.290, BIC = 9455.388. *p < .05, **p < .01, ***p < .001.

Table 3.1

Demographic Characteristics of Couples Included in Factor Analyses

Variable	Mean (SD)/n (%)	
	Women (n = 338)	**Spouses (n = 338)**
Age	53.3 (11.4) (29~81)	55.0 (12.1) (26-90)
Highest education		
High school	15 (4.4)	14 (4.1)
Some college/technical training	80 (23.7)	84 (24.9)
Bachelor's degree	136 (40.2)	135 (39.9)
Master's degree	81 (24.0)	74 (21.9)
Doctoral degree	26 (7.7)	31 (9.2)
Employment status		
Working full time	89 (26.3)	218 (64.5)
Working part-time	64 (18.9)	25 (7.4)
Not working	44 (13.0)	8 (2.4)
Retired	78 (23.1)	83 (24.6)
Other	63 (18.6)	4 (1.2)
Ethnic group		
Caucasian	296 (87.6)	300 (88.8)
Other*	41 (12.2)	38 (11.2)
Years married	22.9 (13.0) (0~56yrs)	
Annual household income (n=331)		
$150,000 or more	103 (30.5)	
$100,000 - $149,999	89 (26.3)	
$75,000 - $99,999	56 (16.6)	
$35,000 - $74,999	61 (18.0)	
< $35,000	14 (4.1)	
Stages of breast cancer (n=336)		
Stage 0	52 (15.4)	
Stage I	131 (38.8)	
Stage II	121 (35.8)	
Stage III	32 (9.5)	
Months since diagnosis	3.3 (1.3)	
Surgery for breast cancer (yes)	287 (84.9)	

Note. *****Other ethnic groups include: African American, Hispanic, Pacific Islander, Asian, etc.

Table 3.2

Descriptive Statistics of 16 Selected MIS Items from Expert Panel Review

Items	Women (n =338)	Spouses (n = 338)
	Mean (SD)	Mean (SD)
Item 1 Keep the communication open between us about the breast cancer.	4.64 (0.71)	4.64 (0.65)
Item 3 When we don't understand what the other is feeling about the breast cancer, we try to figure it out together.	3.90 (1.12)	3.69 (1.02)
Item 5 We check in with each other to see how things are going with the breast cancer.	3.51 (1.13)	3.64 (1.06)
Item 7 We spend a lot of time talking about how things are going with the breast cancer.	3.18 (1.12)	3.39 (1.01)
Item 10 We try to support each other's feelings about the breast cancer.	4.53 (0.84)	4.51 (0.74)
Item 12 We don't talk together about the sadness I feel about the breast cancer.	3.43 (1.26)	3.08 (1.23)
Item 14 We confide in each other about the breast cancer.	4.02 (1.07)	4.10 (0.95)
Item 19 We talk about tense things about the breast cancer.	3.62 (1.18)	3.62 (1.02)
Item 20 We maintain a hopeful outlook about the breast cancer.	4.64 (0.65)	4.66 (0.57)
Item 21 We skip over negative feelings about the breast cancer.	3.27 (1.10)	3.34 (1.06)
Item 23 We limit our talk together about difficult issues caused by the breast cancer.	3.73 (1.14)	3.79 (0.98)
Item 25 We try as a couple to keep a positive attitude about the breast cancer.	4.60 (0.69)	4.63 (0.65)
Item 26 We talk a lot together about the breast cancer.	3.40 (1.13)	3.57 (0.99)
Item 30 We don't talk much about the breast cancer.	3.40 (1.23)	3.57 (1.06)
Item 31 We avoid discussing our fear about the breast cancer.	3.54 (1.17)	3.66 (1.01)
Item 32 We try to see the lighter side of things about the breast cancer.	4.06 (0.95)	3.79 (1.00)

Note. Items 12, 21, 23, 30, and 31 are reverse scored.

Table 3.3

Correlations of 16 Selected MIS Item Scores from Expert Panel Review for Diagnosed Women

Observed variable	1	3	5	7	10	12	14	19	20	21	23	25	26	30	31
Item 1 Keep comm open															
Item 3 Figure out the other's feeling	0.516**														
Item 5 Check in with each other	0.462**	0.640**													
Item 7 Spend time talking	0.386**	0.482**	0.539**												
Item 10 Support each other	0.499**	0.567**	0.468**	0.364**											
Item 12 Don't talk about sadness	0.438**	0.468**	0.372**	0.342**	0.333**										
Item 14 Confide in each other	0.490**	0.673**	0.565**	0.473**	0.518**	0.522**									
Item19 Talk about tense things	0.420**	0.535**	0.481**	0.464**	0.430**	0.427**	0.503**								
Item20 Maintain hopeful outlook	0.237**	0.198**	0.185**	0.028	0.362**	0.070	0.216**	0.151**							
Item21 Skip negative feelings	0.268**	0.230**	0.220**	0.261**	0.263**	0.487**	0.260*	0.365**	-0.012						
Item23 Limit talk @ difficult issues	0.432**	0.341**	0.269**	0.324**	0.340**	0.522**	0.427**	0.374**	0.178**	0.460**					
Item25 Keep positive attitude	0.283**	0.240**	0.207**	0.145**	0.365**	0.163**	0.230**	0.221**	0.571**	0.006	0.203**				
Item26 Talk a lot together	0.410**	0.503**	0.450**	0.692**	0.340**	0.355**	0.458**	0.531**	0.084	0.240**	0.347**	0.168**			
Item30 Don't talk much	0.424**	0.458**	0.444**	0.569**	0.334**	0.426**	0.440**	0.470**	0.079	0.381**	0.468**	0.161**	0.700**		
Item31 Avoid discussing fears	0.474**	0.476**	0.376**	0.339**	0.415**	0.552**	0.516**	0.453**	0.248**	0.474**	0.583**	0.176**	0.429**	0.541**	
Item32 Try to see lighter side	0.264**	0.222**	0.253**	0.097	0.302**	0.051	0.185**	0.089	0.397**	-0.028	0.113*	0.451**	0.149*	0.041	0.048

Note. **Correlation is significant at the 0.01 level (2-tailed; $p < .01$); *correlation is significant at the 0.05 level (2-tailed, $p < .05$). Items 12, 21, 23, 30, and 31 are reverse scored.

Table 3.4

Correlations of 16 Selected MIS Item Scores from Expert Panel Review for Spouses

Observed variable	1	3	5	7	10	12	14	19	20	21	23	25	26	30	31
Item 1 Keep comm open															
Item 3 Figure out the other's feeling	0.441**														
Item 5 Check in with each other	0.262**	0.466**													
Item 7 Spend time talking	0.251**	0.370**	0.416**												
Item 10 Support each other	0.429**	0.466**	0.390**	0.252**											
Item 12 Don't talk about sadness	0.156**	0.336**	0.260**	0.097**	0.221**										
Item 14 Confide in each other	0.460**	0.509**	0.470**	0.324**	0.490**	0.364**									
Item19 Talk about tense things	0.216**	0.327**	0.323**	0.388**	0.321**	0.230**	0.392**								
Item20 Maintain hopeful outlook	0.230**	0.189**	0.186**	0.082	0.333**	0.158**	0.303**	0.157*							
Item21 Skip negative feelings	0.048	0.194**	0.193**	0.134*	0.130*	0.303**	0.205*	0.263**	-0.027						
Item23 Limit talk @ difficult issues	0.265**	0.287**	0.362**	0.214**	0.312**	0.411**	0.374**	0.268**	0.236**	0.328**					
Item25 Keep positive attitude	0.304**	0.187**	0.232**	0.049	0.366**	0.180**	0.288**	0.166**	0.560**	-0.039	0.259**				
Item26 Talk a lot together	0.231**	0.336**	0.357**	0.623**	0.249**	0.199**	0.329**	0.420**	0.159**	0.256**	0.297**	0.080			
Item30 Don't talk much	0.305**	0.322**	0.315**	0.528**	0.281**	0.252**	0.346**	0.419**	0.118*	0.332**	0.395**	0.045	0.656**		
Item31 Avoid discussing fears	0.286**	0.401**	0.377**	0.316**	0.338**	0.349**	0.449**	0.371**	0.226**	0.389**	0.553**	0.189**	0.402**	0.484**	
Item32 Try to see lighter side	0.211**	0.169**	0.297**	0.139*	0.277**	0.143**	0.245**	0.137*	0.388**	-0.066	0.208**	0.400**	0.188**	0.079	0.188**

Note. **Correlation is significant at the 0.01 level (2-tailed; $p < .01$); *correlation is significant at the 0.05 level (2-tailed, $p < .05$). Items 12, 21, 23, 30, and 31 are reverse scored.

Table 3.5

Model Fit Indices of Competing Models

Competing model	Group	**Model fit indices**						
		$\chi^2(df)$	Robust CFI	Robust RMSEA	SRMR	AIC	BIC	Sample-size adjusted BIC
2-factor model	women	59.346(39)	0.983	0.049	0.044	6428.014	6561.242	6437.643
	spouses	72.488(39)	0.976	0.050	0.042	9262.162	9411.260	9287.546
3-factor model	women	93.432(66)	0.979	0.045	0.048	7844.863	7978.091	7854.492
	spouses	116.741(66)	0.964	0.049	0.054	11558.067	11707.165	11583.451
4-factor model	women	58.406(39)	0.984	0.048	0.042	6444.229	6577.456	6453.857
	spouses	65.152(39)	0.981	0.045	0.043	9306.290	9455.388	9331.674

Note. $\chi 2$ = Chi-square statistic; df = degrees of freedom; CFI = Comparative Fit Index; RMSEA = Root Mean Square Error of Approximation; SRMR = Standard Root Mean Square Residual; AIC = Akaike information criterion; BIC = Bayesian information criteria. All the $\chi 2$ in this table has a p-value < .05. CFI>.95, RMSEA < .05, and SRMR < .08 indicate satisfactory model fit; a lower AIC or BIC value indicates a better model fit.

Table 3.6

Factor Loadings of Items for 4-factor Model

Dimensions and items	Standardized factor loadings	
	Women	**Spouses**
Factor 1: Keeping the communication open with each other about breast cancer		
Item 1: We keep the communication open between us about the breast cancer.	0.68***	0.63***
Item 3: When we don't understand what the other is feeling about the breast cancer, we try to figure it out together.	0.79***	0.70***
Item 5: We check in with each other to see how we are doing about the breast cancer.	0.61***	0.65***
Item 14: We confide in each other about the breast cancer.	0.84***	0.77***
Factor 2: Sharing a positive outlook on breast cancer		
Item 20: We maintain a hopeful outlook about the breast cancer.	0.78***	0.71***
Item 25: We try as a couple to keep a positive attitude about the breast cancer.	0.76***	0.80***
Factor 3: Avoiding discussion of negative thoughts and feelings about breast cancer		
Item 21: We skip over negative feelings about the breast cancer.	0.59***	0.46***
Item 23: We limit our talk together about difficult issues caused by the breast cancer.	0.75***	0.66***
Item 31: We avoid discussing our fear about the breast cancer.	0.78***	0.85***
Factor 4: Spending sufficient time together talking about breast cancer		
Item 7: We spend a lot of time talking about how things are going with the breast cancer.	0.85***	0.81***
Item 26: We talk a lot together about the breast cancer.	0.77***	0.77***
Item 30: We don't talk much about the breast cancer.	0.89***	0.86***
Covariances between factors in women: F1~F2: 0.58***; F1~F3: 0.73***; F1~F4: 0.73***; F2~F3: 0.36***; F2~F4: 0.24*; F3~F4: 0.80***. Covariances between factors in spouses: F1~F2: 0.47***; F1~F3: 0.66***; F1~F4: 0.61***; F2~F3: 0.29***; F2~F4: 0.13; F3~F4: 0.66***.		

Note. *$p < .05$, **$p < .01$. ***$p < .001$. F = factor.

Expert Review Sheet

Instructions

The purpose of the expert panel review is to select content-valid items from the Mutuality and Interpersonal Sensitivity Scale (MIS) to measure a new concept named Common Dyadic Coping (CDC).

MIS is a self-report questionnaire which was originally designed to measure a couple's *communication around breast cancer;* it consisted of an original pool of 32 items with two subscales: *Communication* subscale and *Expressing Sad Feelings* subscale.

Please first carefully read the definitions provided below for *Common Dyadic Coping* and *Coping*. After that, please review each MIS item listed in the sheet and decide if each item could be a potential indicator of *Common Dyadic Coping*.

For each item, select **one option** from the following**:** "Yes, relevant," "No, not relevant," or "Maybe", and **provide your reasons** for that option (For example, for "Yes" - "This is problem avoidance, a typical type of coping"; for "No" – "This is just a thought/belief, not a purposive action to cope with the problem.)

Definition of the target concept

Common Dyadic Coping is the conjoint effort of both partners in the couple to deal with breast cancer related stress by means of stress communication, sharing of feelings and concerns, relaxing together, joint problem-solving, joint cognitive appraisal/restructuring, use of available supports and resources, or other purposeful actions.

Table 3.7 MIS item selection for relevance to measure Common Dyadic Coping

MIS Items	**Relevant to measure CDC?**			**Your reasons**
	Yes	No	Maybe	
1. Talking together about things other than the breast cancer makes things better.				
2. We approach the breast cancer with the same thoughts and feelings.				
3. My personal feelings about the breast cancer are not what we talk about together.				
4. We think that talking about the breast cancer only makes things worse.				
5. We confide in each other about the breast cancer.				
6. We talk about tense things about the breast cancer.				
7. We think it's important to not dwell on the				

breast cancer.				
8. Sad thoughts about the breast cancer only make things worse.				
9. We don't talk together about the sadness I feel about the breast cancer.				
10. We don't think the breast cancer affects us much as a couple.				
11. We limit our talk together about difficult issues caused by the breast cancer.				
12. We try to support each other's feelings about the breast cancer.				
13. We spend a lot of time talking about how things are going with the breast cancer.				
14. We don't think it's important to always have common feelings about the breast cancer.				
15. We are comfortable sharing feelings about the breast cancer with each other.				
16. It is difficult for us to agree about how the breast cancer affects us.				
17. We don't talk much about the breast cancer.				
18. We are aware of each other's feelings about the breast cancer, even when we don't have the same feelings.				
19. We understand how each of us is feeling about the breast cancer.				
20. When we don't understand what the other is feeling about the breast cancer, we try to figure it out together.				
21. We avoid discussing our fear about the breast cancer.				
22. We don't view the breast cancer in the same way.				
23. We try as a couple to keep a positive attitude about the breast cancer.				
24. We try to see the lighter side of things about the breast cancer.				
25. We have a common understanding about the breast cancer.				

26. We skip over negative feelings about the breast cancer.				
27. We check in each other to see how we are doing about the breast cancer.				
28. We believe it's important to distract each other from the breast cancer.				
29. We maintain a hopeful outlook about the breast cancer.				
30. We talk a lot together about the breast cancer.				
31. We keep the communication open between us about the breast cancer.				
32. Sad thoughts about the breast cancer are hard for us to talk about together.				

Chapter 4: Common Dyadic Coping in Couples Facing Breast Cancer: Does Congruence Benefit Psychological Adjustment of Patients and Partners?

Abstract

Background: Psychological suffering is prevalent in both women with breast cancer and their spouse caregivers. Less well understood is how couples' coping affects psychological suffering in each member of the dyad. Common dyadic coping and coping congruence were hypothesized to diminish suffering in both women with breast cancer and spouse caregivers.

Methods: Single occasion self-report data were obtained at baseline from 343 diagnosed women and 343 spouse caregivers from a recently completed randomized clinical trial. Study participants were eligible if the woman was diagnosed within 6 months with Stage 0-3 breast cancer and living with a spouse caregiver. Psychological suffering was indicated by depressed mood and anxiety, measured by the Center for Epidemiologic Studies-Depression Scale and the Spielberger State-Trait Anxiety Inventory. Common dyadic coping was measured by a self-reported scale that measured three forms of positive common dyadic coping (open communication about breast cancer, sharing a positive outlook on breast cancer, spending time talking about breast cancer) and one form of negative common dyadic coping (avoiding discussion of negative thoughts and feelings about breast cancer). Congruence was assessed by the absolute difference between women's and spouse's common dyadic coping scores. Multiple linear regression was used to examine the relationships between 1) women's and spouse's perceived common dyadic coping and their psychological suffering; and 2) couple's congruence in common dyadic coping and their psychological suffering.

Results: Participants were predominantly White, middle-aged, highly educated, and fiscally well-off heterosexual couples married for an average of 23.2 years (SD: 12.92). Higher scores on common dyadic coping predicted diminished psychological suffering in both diagnosed women and their spouse caregivers. Women who suffered less scored higher in open communication,

sharing a positive outlook, and scored lower in avoiding negative coping. Spouses who suffered less scored higher in open communication, sharing a positive outlook, spending time talking about breast cancer, and scored lower in avoiding negative coping. Greater congruence in common dyadic coping predicted diminished psychological suffering. Congruence in sharing a positive outlook benefited both members of the dyad. Congruence in avoiding negative coping significantly benefited the patients, whereas congruence in open communication significantly benefited the spouse caregivers.

Conclusion: Common dyadic coping and its congruence in specific areas have potential benefit to couple's psychological adjustment to breast cancer. Future research is needed to examine these results in a more diverse study sample.

Key words: psychological suffering, breast cancer, dyadic coping, coping congruence, spouse

Introduction

An increasing number of women are living with breast cancer due to the increased incidence and survival rate caused by population aging, advances in screening, and early detection and treatment, especially in developed countries (Ahmad, 2019; American Cancer Society, 2019; Momenimovahed & Salehiniya, 2019). Psychological distress is prominent in patients (Kenyon et al., 2014; Carreira et al., 2018). In a recent systematic review, the average prevalence of depression and anxiety in breast cancer patients was 39.9% and 27.2% respectively (Maass et al., 2015). Symptoms of depression were more prevalent than healthy women, especially in the first year after diagnosis (Maass et al., 2015).

For women in committed relationships, the impact of breast cancer often goes beyond the patient and takes a toll on their spouse caregivers. Studies showed that psychological distress was prevalent in both sides of the dyads facing breast cancer, and their distress was highly correlated (Baider, & De-Nour, 1985; Northouse & Swain, 1987; Northouse et al., 1995; Parmelee Streck & LoBiondo-Wood, 2020; Segrin et al., 2007). The mutual influence of emotional distress also spilled over into each other's physical health (Dorros et al., 2010; Segrin et al., 2007). Spouses reported sleep disturbances, eating disorders, affected concentration at work, fear and uncertainty about their wife's illness, and felt overtaxed by the demands of patients' physical caring and emotional support as well as reallocated household duties and child-rearing responsibilities (Northouse et al., 1991; Wellisch et al., 1978; Zahlis & Shands, 1991).

This interdependence and mutuality between partners make breast cancer a "we-stressor" that affects both members in the dyad, and couples often respond as a system rather than as individuals when dealing with the shared stressor (Hagedoorn et al., 2008; Kayser et al., 2007;

Zunkel, 2002). Couples can take a variety of coping forms from the individual level and the dyadic level, among which common dyadic coping is a type that refers to couples' joint coping efforts to maintain stability of the relationship in front of dyadic stress (Bodenmann, 1997). Research has shown that greater "couple identity" (shared identity with a significant other in a committed relationship) facilitated cancer patients' coping self-efficacy and therefore predicted less depression, anxiety, and better functional well-being of the patients (Ahmad et al., 2017). Specific common dyadic coping strategies may include joint information seeking, joint problem-solving, mutual positive reframing, relaxing together, and affectionate mutual support (Bodenmann, 1997, 2008). Multiple studies have evidenced the association between common dyadic coping (in positive forms, such as stress communication, trusting each other, sharing of feelings, joint problem solving) with less psychological distress, better adaptation to illness, and higher marital/relationship satisfaction (Bodenmann, 2005; Falconier et al., 2015; Ştefănuţ et al., 2021; Valente et al., 2021). Negative dyadic coping (such as avoidance of discussing stressors, hiding feelings and denying concerns from each other) was evidenced to associate with higher distress, lower emotional well-being, and lower relationship quality (Bodenmann, 2005; Ştefănuţ et al., 2021; Traa et al., 2015). However, most studies assumed common dyadic coping to be positive; only one study has distinguished common *positive* dyadic coping and common *negative* dyadic coping and assessed their influence separately (Badr et al., 2010).

Not only do the types of dyadic coping influence relationship and health outcomes in couples facing breast cancer, but the degree of their coping *congruence* matters. Dyadic coping congruence has been studied in three forms. The first form examined similarity of personal coping or dyadic coping *between two individuals* in the dyad (e.g., "I make a plan of action"), where each partner' self-perception of their own coping was assessed (Kraemer et al., 2011;

Pakenham, 1998). The second form focused on perceptual congruence, which examined how well each partner understood the other partner's coping, or the perceived similarity of self-coping and the other partner's coping (e.g., compare the wife's response to item "My husband takes on things that I would normally do in order to help me out" and the husband's response to item "I take on things that my wife would normally do in order to help her out.") (Iafrate et al., 2012; Romero et al., 2008). The last form examined congruence in common dyadic coping, which assessed the extent to which both partners coped coherently as a unit using measures with "we" items, such as "we try to cope with the problem together" (Badr et al., 2010; Meier et al., 2019).

Findings on dyadic coping congruence are complex and inconsistent. While some studies found that higher coping congruence predicted better psychological status and higher relationship satisfaction (Kraemer et al., 2011; Meier et al., 2019; Romero et al., 2008; Pakenham, 1998), others did not detect such significant relationships (Iafrate et al., 2012; Merz et al., 2011; Osin et al., 2018; Revenson, 1994). And whether coping congruence was adaptative seemed to depend on which types of coping the couples used. For instance, congruence in positive dyadic coping were more beneficial than congruence in negative dyadic coping (Badr et al., 2010; Merz et al., 2011); congruence in emotion-focused coping was more beneficial than congruence in problem-focused coping (Barbarin et al., 1985; Pakenham, 1998; Revenson, 1994). Berg and Upchurch (2007) further concluded that congruence was only beneficial when couples were both engaged in active coping approaches. However, empirical evidence is insufficient to reach a consistent conclusion on whether and in what circumstances coping congruence is beneficial for couples' adjustment to cancer.

Considering these gaps, the current study will examine the association between common dyadic coping and common dyadic coping congruence and psychological suffering in patients

with early-stage breast cancer and their spouse caregivers. This study will also explore if common dyadic coping and common dyadic coping congruence mediate the relationship between patients' breast cancer stage and couple's psychological suffering. To date no study has examined the mediating effect of dyadic coping in couples facing breast cancer even though a few studies examined individual coping in cancer patients (Langford et al., 2017; Merluzzi et al., 2019). Study hypotheses are summarized below:

1. The use of more *positive* common dyadic coping predicts diminished psychological suffering; the use of more *negative* common dyadic coping predicts greater psychological suffering.
2. Greater *congruence* in common dyadic coping predicts diminished psychological suffering.
3. Couples who are more *congruent* in their use of *positive* common dyadic coping have diminished psychological suffering than couples who are more *congruent* in their use of *negative* common dyadic coping.
4. Common dyadic coping and common dyadic coping congruence mediate the effects of the threat of the cancer (patient's breast cancer stage) on couples' psychological suffering.

Theoretical Framework

Two models guided this study, Bodenmann's Systematic-Transactional Model of Dyadic Coping (Bodenmann, 1995, 1997, 2005) and Krikorian & Limonero's (2012) integrated model of suffering. See **Figure 4.1**. Four assumptions underlie this framework: 1) breast cancer affects both partners in the couple as a "we-stressor"; 2) the cognitive appraisal and coping behaviors to breast cancer related stress are conceptualized from a systematic level in which the couple is

regarded as a unit; 3) common dyadic coping involves both positive and negative modes of coping; and 4) patients' and partners' coping and psychological status impact each other.

Methods

Design

This is a secondary analysis using baseline data obtained in the recently completed Helping Her Heal (HHH) study, a recently completed randomized clinical trial that examined the efficacy of a 5-session psychoeducational intervention targeting marital communication and interpersonal support in women with early-stage breast cancer and their spouse caregivers (Lewis et al., 2019). Human Subjects approval for the current analysis was obtained from University of Washington Institutional Review Board (IRB ID: STUDY00014873).

Study Sample

The study sample consisted of 343 women with breast cancer and their 343 spouse caregivers. Patients were eligible if they: (a) were diagnosed with stage 0-III breast cancer within six months at the point of the study; (b) married or in an intimate relationship six months or longer; (c) could read and write English; and (d) lived within 100 miles of the study center. The spouses were eligible if they were fluent in English (Lewis et al., 2019).

Study Procedure

A total of 2,092 eligible spouse caregivers were initially identified among which 1727 refused to participate in the study. After requesting signed informed consent from both members of the couple in their homes, 343 spouses and patients with breast cancer completed the baseline questionnaires.

Study Measures

Demographic characteristics (e.g., age, ethnicity, education, occupation) and disease

related information (e.g., stage of breast cancer, time of diagnosis, surgery and treatment) were collected from medical record and self-report.

External stressful events in **Figure 4.1** were indicated by patients' stage of breast cancer. Patient' and spouses' psychological suffering was indicated by depressed mood and anxiety, and the measures used are described below. Measures for common dyadic coping and common dyadic coping congruence are also described below. The two members in the couple completed these self-reported measures independently.

Depressed mood. Depressed mood was measured by the Center for Epidemiologic Studies-Depression (CES-D) Scale, including 20 items assessing frequency of symptoms of depression in the past week (e.g., "I felt sad", "I felt that I could not shake off the blues even with help from my family or friends") on a 0-3 rating scale (0 = rarely or none of the time; 3 = most or all of the time). The score was the sum of the 20 questions, which could range from 0 to 60 with higher scores indicating the presence of more depressive symptoms. A score of 16 or above was considered depressed (Radloff, 1977). Internal consistency reliability (Cronbach's alpha) was 0.892 for women and 0.894 for spouse caregivers.

Anxiety. The State subscale of the Spielberger State-Trait Anxiety Inventory (STAI) (Spielberger, 1983) was used to measure women's and spouses' anxiety. It had 20 items at a 4-point Likert scale (1 = not at all; 4 = very much so) that assessed subjective feelings of apprehension, tension, nervousness, and worry at the moment (e.g., "I feel tense", "I am worried"). The total scores could range from 20 to 80, with higher scores indicating greater anxiety. Scores equal to or over 39 indicated clinically significant symptoms (Julian, 2011). Cronbach's alpha was 0.941 for women and 0.935 for spouses.

Common dyadic coping. Common dyadic coping was measured by a 12-item self-report

scale CDC-C that assessed the patient's or spouse's perceptions of how they as a couple coped with breast cancer together (Liu et al., unpublished). It contained four subscales: *keeping the communication open with each other about breast cancer* (referred to as Open Communication,' e.g., "We confide in each other about the breast cancer"), *sharing a positive outlook on breast cancer* (referred to as Positive Outlook,' e.g., "We try as a couple to keep a positive attitude about the breast cancer"), *avoiding discussion of negative thoughts and feelings about breast cancer* (referred to as Avoid Negative,' e.g., "We skip over negative feelings about the breast cancer"), and *spending sufficient time together talking about breast cancer* (referred to as Spend Time Talking, e.g., "We talk a lot together about the breast cancer."). Responses were on a five-point scale (1 = "Never true," 5 = "Always true"). The total scores can range from 12 to 60. Internal consistency (McDonald's omega) of the scale ranged from 0.758 to 0.868 for women and 0.695 to 0.825 for spouses.

In this study, Open Communication, Positive Outlook, and Spend Time Talking were assumed to be *positive* forms of common dyadic coping; Avoid Negative was assumed to be *negative* common dyadic coping. In calculating the total score, the subscale of Avoid Negative was reverse scored. Therefore, a higher CDC-C total score indicated perceived higher scores in positive common dyadic coping (Open Communication, Positive Outlook, and Spend Time Talking) and lower scores in negative common dyadic coping (Avoid Negative). However, the subscale of Avoid Negative coping was not reverse coded; higher scores denoted greater use of Avoid Negative coping.

Common dyadic coping incongruence. Couple's incongruence in common dyadic coping was measured by the average absolute difference between women's and spouses' scores on CDC-C items. Specifically, the incongruence in CDC-C total score was measured by the average

of the absolute value of couple's score difference on all 12 CDC-C items; the incongruence in CDC-C subscale was measured by the average of the absolute value of couple's score difference on items included in this subscale. Larger values reflect greater incongruence.

Statistical Analyses

Analyses were conducted in IBM SPSS Statistics version 28.0.0.0. Before analyses, the data files were prepared by cleaning, checking for missing values, sampling distributions and outliers. No evidence of outliers was found. There were less than 2% missing values on common dyadic coping, depressed mood and anxiety scores in both women's and spouses' data, therefore listwise deletion was used (Graham, 2009). Skewness and kurtosis tests reflected acceptable normality of distribution of these main variables (absolute skewness value ≤ 2 and absolute 'excess' kurtosis ≤ 4) (Kim, 2013; Mishra et al., 2019), therefore no data transformation was conducted.

Statistical analysis proceeded through five steps. **First,** descriptive statistics of the study sample were computed (means, standard deviations, and ranges for continuous variables; frequencies and percentages for categorical variables) for women's and spouses' demographic variables, common dyadic coping (and the subscales), common dyadic coping incongruence, and depressed mood and anxiety. Paired t-tests were used to compare the score difference between women and spouses in the dyads. **Second,** we performed bivariate analyses (correlations for continuous variables and t-test or one-way ANOVA for categorical variables) to detect significant demographic or disease-related covariates that were associated with women's and spouses' depressed mood and anxiety, which needed to be controlled for in the subsequent multiple linear regression models. Correlations between predictor variables were examined for sources of multicollinearity. The criteria of Variance inflation factor (VIF) > 10 and Tolerance <

0.1 were also used to indicate multicollinearity (Dormann et al., 2013; Regorz, 2020). No multicollinearity was detected in any of the analyses.

Third, multiple linear regression was used to predict psychological suffering as a function of common dyadic coping or coping incongruence. Regression models were run for women's data and spouses' data separately. Depressed mood or anxiety was the dependent variable; participants' total common dyadic coping score or total incongruence score was entered into the model separately as the predictor. After that, each common dyadic coping subscale score and subscale incongruence score was entered into the model separately as the predictor. Each model only contained one total score or one subscale score as the predictor. For each regression model, significant covariates were also entered into the model to control for their effects on the dependent variable.

Fourth, an interaction term between couple's common dyadic coping score and coping incongruence score was added to each regression model to test if there were significant interactions. Common dyadic coping and incongruence total score and each subscale score were centered to the mean (subtracting the mean score from each individual score and calculate the average) to alleviate multicollinearity caused by the interaction term. The interaction between the total scores and between each subscale scores were examined by turn.

To add to our understanding, significant interactions were graphically plotted to show the linear relationship between coping incongruence and psychological suffering at different levels of common dyadic coping (low level: mean – SD; medium level: mean; high level: mean + SD) (Aiken & West, 1991).

Fifth, the mediation effects of common dyadic coping and common dyadic coping congruence were examined according to Baron & Kenny's (1986) classical causal steps and

Hayes' bootstrapping method using the PROCESS package version 4.1 in SPSS (Hayes, 2022).

Results

Sample Characteristics

Demographic and disease related information is presented in **Table 4.1**. All couples were heterosexual, married, and in relationship for an average of 23.2 years (SD: 12.92; range: 0.42~56.67). Patients' average age was 53.36 (SD: 11.39; range: 29~81); spouses' average age was 54.94 (SD: 12.11; range: 26~90). Most couples were White (88%), had at least college education (70%), and had annual household income no less than $75,000 (74.5%). Forty-five percent of the patients and 72% of the spouses were working full time or part-time. Other patients were not working (12.8%), retired (23.3%), or taking medical leave of absence (9.3%).

The majority of women were diagnosed with Stage I or II breast cancer: 15.8% had Stage 0, 39% had Stage I, 35.8% had Stage II, and 9.4% had Stage III disease. The average length of time since diagnosis was 3.32 months (SD: 1.25). Most women had received surgery for breast cancer (84.8%; 53.3% lumpectomy, 36.8% mastectomy) and received treatment for cancer in the past four months (73.8%; 55.8% chemotherapy, 25% radiation, 10.4% hormone therapy, 6.8% neoadjuvant therapy). Many women (68.3%) reported symptoms or side effects from therapy, and 31.8% had other diagnosed chronic illnesses. A small portion of the women and spouses had received individual counseling (13.1%, 4.7%) or joined a cancer support group (10.8%, 3.8%).

Level of Patients' and Spouses' Psychological Suffering and Common Dyadic Coping

Table 4.2 presents the means, standard deviations (SDs), and ranges of couple's depressed mood, anxiety, and common dyadic coping scores, as well as the paired t-test results between patients and spouses.

Forty-four percent of patients and 32% of the spouses scored ≥ 16 on the CES-D,

indicating clinically elevated levels of depressed mood (Radloff, 1977). A total of 39.7% of the patients and 30.6% of the spouses scored ≥ 39 in STAI, suggesting significant anxiety symptoms (Julian, 2011). Patients' depressed mood and anxiety scores were significantly higher than spouses' scores ($p < .01$). Patients' common dyadic coping scores ranged from 17 to 60, with a mean score of 45.91 (SD: 8.3). Spouses' common dyadic coping scores ranged from 26 to 60, with a mean score of 46.73 (SD: 6.8). The couple's common dyadic coping total score was comparable, as well as most of the subscale scores. The only significant difference in subscale was that spouses' scores on "spend time talking" were significantly higher than patients' scores ($p < .01$); however, the effect size was small (Cohen's $d < 0.2$) (Sullivan & Feinn, 2012). Couples' common dyadic coping congruence scores ranged from 0.08 to 2.58, with an average of 0.87 and a SD of 0.36.

Selection of Significant Covariates

Based on bivariate analyses, seven factors were significantly associated with patients' psychological suffering: age ($r = -0.170$, $p < .01$) and years in relationship ($r = -0.176$, $p < .01$) were negatively correlated with depressed mood. Lower household income was associated with higher depressed mood and anxiety ($p < .001$). Currently working patients had significantly lower depressed mood than non-working patients ($t_{(339)} = -2.05$, $p < .05$). Patients who experienced symptoms or side effects from therapy ($t_{(337)} = 4.443$, $p < .001$) reported higher depressed mood. Patients who had other diagnosed chronic illnesses reported significantly higher depressed mood ($t_{(187)} = 2.99$, $p < .01$) and anxiety ($t_{(341)} = 3.36$, $p < .001$). Patients who were receiving individual counseling also reported significantly higher depressed mood ($t_{(339)} = 4.67$, $p < .001$) and anxiety ($t_{(341)} = 3.36$, $p < .001$). These factors were controlled for as covariates in the regression models when predicting patients' psychological suffering.

Five factors were significantly associated with spouses' psychological suffering: older spouses had lower depressed mood ($r = -0.205$, $p < .001$) and anxiety ($r = -0.163$, $p < .01$). Spouses in longer relationship with the patients had lower depressed mood ($r = -0.113$, $p < .05$). Lower household income was associated with higher depressed mood and anxiety ($p < .05$). Currently working spouses had significantly higher depressed mood ($t_{(194)} = 2.74$, $p < .01$) and anxiety ($t_{(341)} = 2.10$, $p < .05$). Spouses who joined a cancer support group also had significantly higher depressed mood ($t_{(336)} = 2.92$, $p < .01$). These factors were controlled for in the regression models when predicting spouses' psychological suffering.

Results of Hypotheses Testing

Table 4.3 contains Pearson correlation coefficients between common dyadic coping, common dyadic coping congruence, and patients' and spouses' psychological suffering. **Tables 4.4-4.7** contain results predicting patients' and spouses' psychological suffering from couple's common dyadic coping and coping incongruence predicted patients' and spouses' psychological suffering. A graphic summary of the relationships between these variables in patients and spouses are illustrated in **Figure 4.2 and 4.3**, respectively.

Hypothesis 1: The use of more *positive* common dyadic coping predicts diminished psychological suffering; the use of more *negative* common dyadic coping predicts greater psychological suffering.

In patients, consistent with Hypothesis 1, higher common dyadic coping scores predicted lower scores of depressed mood ($\beta = -0.235$, $p < .001$) and anxiety ($\beta = -0.388$, $p < .001$). In spouses, also consistent with Hypothesis 1, higher common dyadic coping scores predicted lower depressed mood ($\beta = -0.352$, $p < .001$) and anxiety ($\beta = -0.521$, $p < .001$).

Modeling in the subscales of CDC-C showed higher scores in Open Communication and Positive Outlook coping predicted decreased depressed mood and anxiety (*p*s < .001) in both women and spouses. Additionally, higher scores in Avoid Negative coping predicted greater depressed mood and anxiety (*p*s < .001). Further, higher scores in Spend Time Talking predicted decreased depressed mood and anxiety only in spouses (*p*s < .05).

Hypothesis 2: Greater *congruence* in common dyadic coping predicts diminished psychological suffering.

Consistent with Hypothesis 2, couple's higher incongruence in common dyadic coping predicted patients' increased depressed mood (β = 2.667, *p* = .050) and anxiety (β = 3.705, *p* = .044), and also predicted spouses' increased depressed mood (β = 4.153, *p* = .002) and anxiety (β = 4.273, *p* = .008).

Modeling couple's incongruence in the subscales of CDC-C revealed that couple's higher incongruence in Positive Outlook predicted both patients' and spouses' increased depression and anxiety (*p*s < .01). Couple's higher incongruence in Avoid Negative predicted patients' increased anxiety (*p* < .05). And couple's higher incongruence in Open Communication predicted spouses' increased depressed mood and anxiety (*p*s < .05).

Hypothesis 3: Couples who are more *congruent* in their use of *positive* common dyadic coping have diminished psychological suffering than couples who are more *congruent* in their use of *negative* common dyadic coping.

Counter to prediction, the interaction between common dyadic coping and coping incongruence total score was not significant (*p* > .1) for both patients and spouses. However, the subscale analyses revealed a significant interaction between patient reported Positive Outlook coping and couple's coping incongruence when predicting patients' depressed mood (*p* = .039)

and anxiety ($p < .001$). See **Figure 4.4.** For instance, in patients with high (mean + SD)/mean Positive Outlook coping score, greater incongruence predicted increased anxiety; whereas in patients with low (mean - SD) Positive Outlook coping score, greater incongruence predicted decreased anxiety. No significant interactions occurred between coping incongruence and other subscales of common dyadic coping.

Hypothesis 4: Common dyadic coping and common dyadic coping congruence mediate the effects of the threat of the cancer (patient's breast cancer stage) on couples' psychological suffering.

Counter to Hypothesis 4, the mediation effects of common dyadic coping and common dyadic coping congruence were not significant. Based on the causal steps to test mediation by Baron & Kenny (1986), mediation requires four conditions to be met: (1) the independent variable must significantly affect the mediator; (2) the independent variable must significantly affect the dependent variable; (3) the mediator must significantly affect the dependent variable after controlling for the independent variable; (4) the effect of the independent variable on the dependent variable after controlling for the mediator (direct effect) should be less than the effect of the independent variable on the dependent variable (total effect). Using this method, we first regressed the presumed mediator, common dyadic coping and common dyadic coping congruence, on patient's breast cancer stage. The associations were not significant ($p > .05$). We then regressed patient's and spouse's psychological suffering on patient's breast cancer stage. The associations were still not significant ($p > .05$). Although condition (3) was met ($p < .05$) in the analysis, we could not establish mediation based on this approach.

However, Hayes (2009) and others (Memon et al., 2018; Zhao et al., 2010) criticized Baron & Kenny's (1986) approach for causing researchers to miss important findings when

strictly following the Baron-Kenny criteria. They argued that there is no need for an existing significant effect from the predictor to the outcome to establish mediation (Hayes, 2009; Memon et al., 2018; Zhao et al., 2010). One possible explanation is that two or more indirect effects may coexist but in opposite directions, making the total effect cancelled out (Hayes, 2009). Therefore, we tested the mediator's indirect effect directly using bootstrapping method (Hayes, 2022).

Analyses revealed that the presumed mediation effects of common dyadic coping and common dyadic coping congruence were not significant. However, when examining the mediation effects of the common dyadic coping subscales, Spend Time Talking significantly mediated the effect of patient's breast cancer stage on spouses' anxiety (indirect effect estimate: -0.25; 95% CI: [-0.59, -0.02], based on 5000 bootstrap samples). This mediation effect still held after controlling for spouses' age and employment status (effect estimate: -0.26; 95% CI: [-0.62, -0.01], based on 5000 bootstrap samples).

Discussion

The current study examined the associations between common dyadic coping, common dyadic coping congruence, and psychological suffering of women with early-stage breast cancer and their spouse caregivers. As predicted, a higher level of positive common dyadic coping (open communication and sharing a positive outlook about breast cancer) predicted diminished psychological suffering, and a higher level of negative common dyadic coping (avoid discussing negative thoughts and feelings about breast cancer) predicted greater psychological suffering in both women and spouses. Also as predicted, couples who were more congruent in common dyadic coping suffered less.

The mean score of CES-D and proportion of patients with clinically significant depressive symptoms (15.17; 44%) were higher than that reported in other studies using the same measure

in mainly early-stage breast cancer patients (8.52-11.61; 27.9%-29%) (Kraemer et al., 2011; Lewis et al., 2008; Rottmann et al., 2015; Schlegel et al., 2012). Patients' mean CES-D score and proportion with clinically significant depressive symptoms were also higher than that in healthy women (7.5; 13.8%) (Ochs-Balcom et al., 2013). The percentage of patients with significant symptoms of anxiety (39.7%) in our study was also greater than the average prevalence (27.2%) of anxiety reported in a systematic review in breast cancer patients after treatment (Maass et al., 2015). The mean CES-D score of spouses (12.28) was higher than that in similar studies investigating partners of women with early-stage breast cancer (8.54-9.9) (Lewis et al., 2008; Rottmann et al., 2015).

Few studies to date have examined the influence of common dyadic coping on psychological distress in couples facing breast cancer. Our findings are consistent with studies by Rottmann et al. (2015) and Meier et al. (2019) who also found that a higher use of positive forms of common dyadic coping (conjoint problem-coping, problem discussion, positive reframing, relaxing, and affectionate support) was associated with less psychological distress for both patients with early-stage breast cancer and their partners. Our results are also consistent with the study by Badr et al. (2010) who similarly detected a significant association between higher use of negative common dyadic coping (avoidance and withdrawal) and greater cancer-related distress in both patients and partners. Badr et al. (2010) did not detect a significant association but observed a statistical trend linking higher positive common dyadic coping use with higher distress in patients and lower distress in partners. However, their study investigated couples facing metastatic breast cancer, not early-stage breast cancer.

In addition to common dyadic coping, couple's congruence in common dyadic coping also predicted lower psychological suffering. Congruence in sharing a positive outlook about breast

cancer predicted even lower psychological suffering in patients. The association between couple's higher coping congruence and patients' decreased distress has been reported in previous studies in couples facing breast cancer, especially when couples were congruent in using emotion-focused coping and approach-oriented coping (Ben-Zur, Gilbar, & Lev, 2001; Kraemer et al., 2011; Meier et al., 2019; Romero et al., 2008). For instance, Ben-Zur et al. (2001) reported that the patient suffered more when the couple was not on the same page in the attempt of denying the situation or venting emotions. Kraemer et al. (2011) found that patients' depressed symptoms decreased the most over time when both partners engaged in active instead of avoidant coping.

Our study added to the literature by finding that couple's congruence in *avoidance* also predicted patient's diminished distress. This result runs contrary to Manne et al.'s (2006) finding that mutual avoidance communication predicted greater distress in both patients and partners. Several reasons may explain the difference. First, Berg and Upchurch (2007) pointed out the importance of considering the context for couple's dyadic coping- it can vary at different life stage and change along with the unfolding of illness stages, the emergent needs of the patient, and the interactions of the couple with the stressor. Research revealed that women with early-stage breast cancer and their spouses experience the most fear and distress initially, which diminished the further they were from the time of diagnosis (Hagedoorn et al., 2008; Cohee et al., 2016). It is possible that mutual avoidance is temporarily protective when the couple is in an early stage learning about the diagnosis. Second, whether mutual avoidance is beneficial may depend on a patient's needs. If the patient wants to hide and withdraw from talking about breast cancer related issues, the spouse's similar withdrawal may be comforting for the patient. If the patient has a high desire to express her feelings but the husband avoids them, the patient's

distress could escalate. This is in line with Manne et al.'s finding that a demand-withdraw communication pattern was associated with greater distress for both patients and spouses. Kraemer et al. (2011)'s study supported this result by finding that in the same "low wife avoidance coping" and "high wife avoidance coping" group, when the husband also had low or high avoidance coping, the patient reported the least depressive symptoms over time.

Our study for the first time observed a significant association between couple's coping congruence and *spouses*' decreased suffering. Prior studies on coping congruence predominantly focused on patients, not spouses. The only other study that assessed spouses' outcomes found no significant relationship between couple's coping congruence and spouses' distress (Meier et al., 2019). This difference may be attributable to participants' different cultural backgrounds (Switzerland versus USA) or the choice of measure of common dyadic coping that was used. From the subscale analysis, we found significant association between couple spent time talking about breast cancer and spouses' decreased suffering, and between couple's higher congruence in open communication and spouses' decreased suffering. Mediation analysis further revealed that spending time talking about breast cancer indirectly reduced the effect of patient's breast cancer stage on spouses' anxiety. These relationships were not significant in patients. The patient-partner role and the gender role may help explain the difference. Badr (2004)'s study in healthy couples and couples facing chronic illness revealed that who (the wife or the husband) is sick seems to affect dyadic coping patterns: When wives are sick, they are more likely to use avoidance coping and protective buffering; when husbands are the ill ones, they tend to actively engage their wives and ask for more network support to help themselves feel more in control. In our study, it is possible that spouses need this confiding and communication time for personal coping with wife's illness, such that he would have the opportunity to express his concerns

related to wife's illness, show care to wife, and to learn about how his wife is thinking and feeling. In this way may they gain more sense of control and alleviate their anxiety.

This study had several limitations. First, our study sample included predominantly White, highly educated, and well-off heterosexual couples. They were also middle-aged and were in their dyadic relationship an average of twenty-three years. Interpretation of study results should be limited to this population. Second, measures for common dyadic coping and psychological suffering were self-reported, making the data at potential risk for subjective bias. Future research would benefit from using more objective measures. Third, we used single occasion data and could only observe associations at one time point. Longitudinal research is needed to observe the changes of the relationships over time and to establish any causal inference. Fourth, although we controlled for multiple covariates in the analysis, other factors that were not measured may have influenced the observed results. For instance, patient's and partner's previous coping styles, marriage quality or relationship satisfaction, and illness-determined physical and psychological status, could possibly influence the couple's common dyadic coping and the extent to which common dyadic coping could affect benefit psychological suffering and the couple's relationship. Future research should consider the impact of these factors. Finally, when testing the mediation effect, we used breast cancer stage as the indicator of external stressful event. Future research should consider other indicators of threat as sources of couple's shared external stress.

Conclusion

Higher levels of positive common dyadic coping and lower levels of negative common dyadic coping predicted lower psychological suffering in couples facing breast cancer. Couple's congruence in common dyadic coping, especially in sharing a positive outlook about breast

cancer, predicted patients' and caregivers' lower psychological suffering. Spouses who spent more time talking about breast cancer with their wives suffered less. Study results have implications for messages health care providers can offer to patients and caregivers.

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Figure 4.1

Theoretical Framework

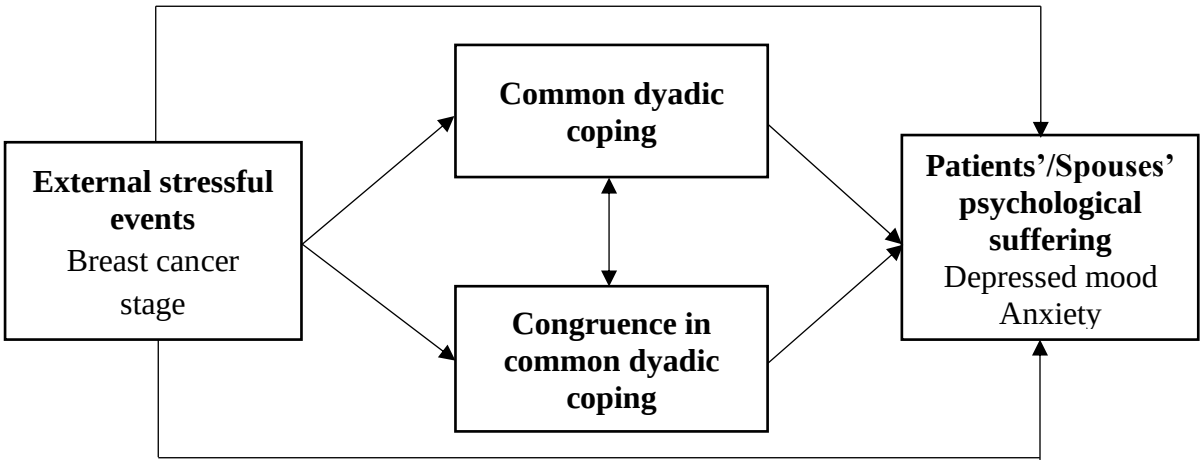
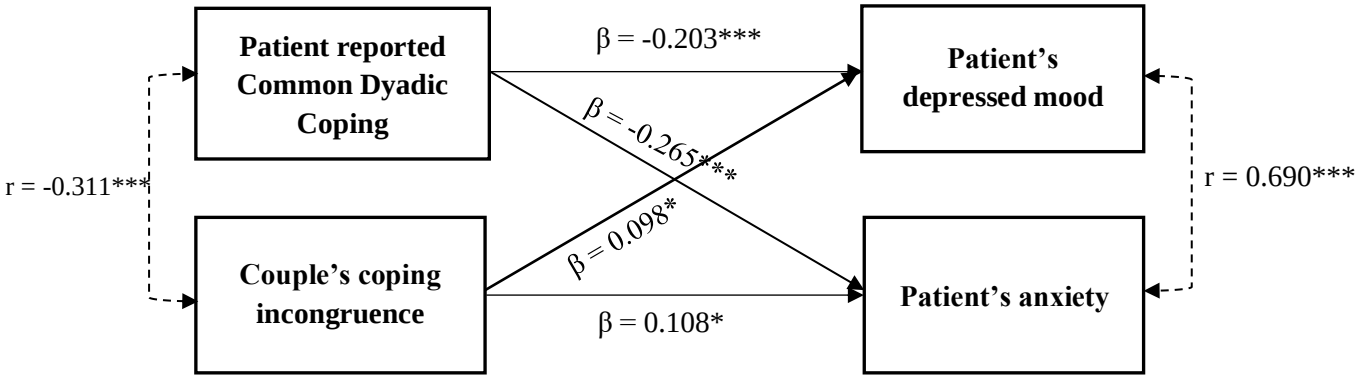


Figure 4.2

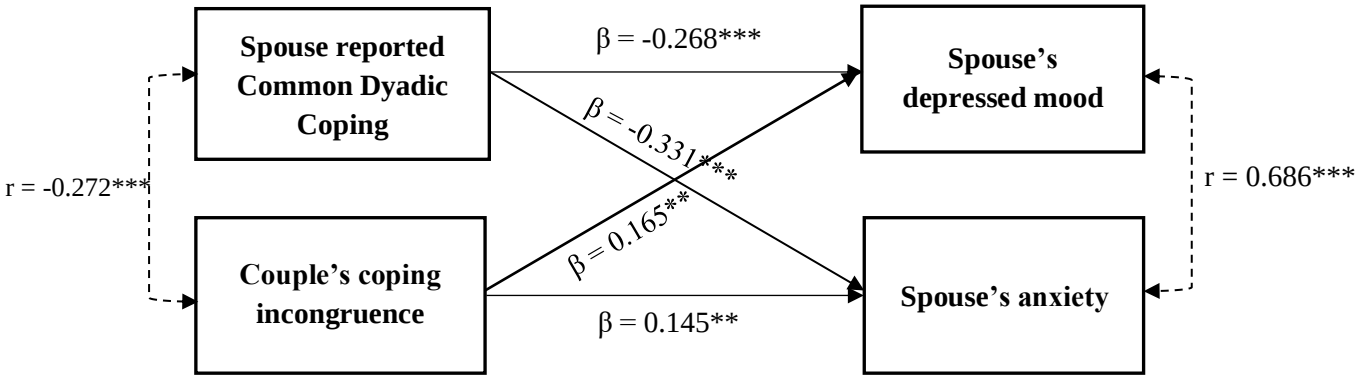
Relationships Between Common Dyadic Coping, Common Dyadic Coping Congruence, and Psychological Suffering in Women with Breast Cancer



Note. β = standardized regression coefficient. r = Pearson correlation coefficient. *p < .05, **p < .01, ***p < 0.001.

Figure 4.3

Relationships Between Common Dyadic Coping, Common Dyadic Coping Congruence, and Psychological Suffering in Spouses



Note. β = standardized regression coefficient. r = Pearson correlation coefficient. **p* < .05, ***p* < .01, ****p* < 0.001.

Figure 4.4

Interaction Between Patient Reported Sharing a Positive Outlook Coping and Couple's Coping Congruence When Predicting Patient's Psychological Suffering

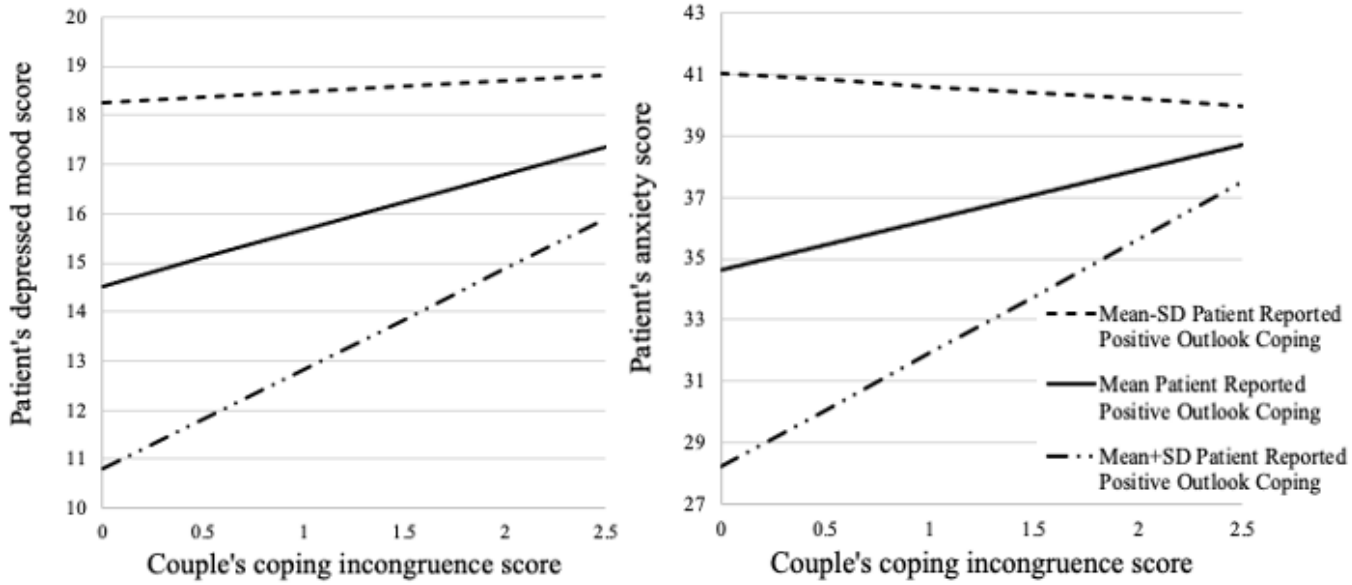


Table 4.1

Demographic and Illness Related Characteristics of the Study Sample

Characteristic	M(SD)/N(%)
Age (years)	
Patient	53.36 (11.39)
Spouse (n = 342)	54.94 (12.11)
Ethnicity (White)	
Patient (n = 342)	301 (88.0%)
Spouse	305 (88.9%)
Employment status (currently working)	
Patient	156 (45.5%)
Spouse	247 (72.0%)
Education (college and above)	
Patient	248 (72.3%)
Spouse	243 (70.8%)
Years in relationship	23.20 (12.92)
Household income (n = 336)	
$150,000 or more	103 (30.7%)
$75,000 - $149,999	147 (43.8%)
< $75,000	78 (23.2%)
Stage of breast cancer (n = 341)	
Stage 0	54 (15.8%)
Stage I	133 (39.0%)
Stage II	122 (35.8%)
Stage III	32 (9.4%)
Months since diagnosis	3.32 (1.25)
Surgery for breast cancer (yes)	291 (84.8%)
Treatment for cancer within last 4 months (yes) (n = 340)	251 (73.8%)
Symptoms or side effects from therapy (yes) (n = 341)	233 (68.3%)
Any other diagnosed chronic illnesses (yes)	109 (31.8%)
Receiving individual counseling (yes)	
Patient	45 (13.1%)
Spouse	16 (4.7%)
Participating in cancer support group (yes)	
Patient	37 (10.8%)
Spouse	13 (3.8%)

Table 4.2

Level of Patients' and Spouses' Psychological Suffering and Common Dyadic Coping

Subscale	Patients		Spouses		Possible range	Paired t-test statistic	*p*-value
	M (SD)	Range	M (SD)	Range			
Depressed mood (CES-D)	15.17 (9.74)	0-45	12.28 (8.85)	0-41	0-60	4.659	<.001
Anxiety (STAI)	36.51 (12.18)	20-77	34.01 (10.65)	20-72	20-80	3.120	0.002
CDC total score	45.91 (8.30)	17-60	46.73 (6.80)	26-60	12-60	-1.840	0.067
Open communication	16.10 (3.39)	5-20	16.11 (2.87)	6-20	4-20	-0.016	0.987
Positive outlook	9.26 (1.20)	4-10	9.30 (1.07)	4-10	2-10	-0.608	0.543
Spend time talking	10.00 (3.06)	3-15	10.53 (2.63)	3-15	3-15	-2.940	0.004
Avoiding negative	7.44 (2.80)	3-15	7.19 (2.39)	3-15	3-15	1.455	0.146

Note. SD = standard deviation. CES-D = Center for Epidemiological Studies–Depression Scale. STAI = Spielberger State-Trait Anxiety Inventory. CDC = Common Dyadic Coping.

Table 4.3

Correlations among CDC, CDC Incongruence, and Couple's Psychological Suffering

Variable	Patient CDC (1)	Spouse CDC (2)	CDC incongruence (3)	Patient CES-D (4)	Spouse CES-D (5)	Patient STAI (6)	Spouse STAI (7)
1	—						
2	0.426***	—					
3	-0.311***	-0.272***	—				
4	-0.221***	-0.176**	0.122*	—			
5	-0.114*	-0.310***	0.224***	0.264***	—		
6	-0.274***	-0.199***	0.142**	0.690***	0.170**	—	
7	-0.201***	-0.355***	0.191***	0.217***	0.686***	0.163**	—

Note. CDC = Common Dyadic Coping. CES-D = Center for Epidemiological Studies–Depression Scale. STAI = Spielberger State-Trait Anxiety Inventory. *$p < .05$, **$p < .01$, ***$p < .001$.

Table 4.4

Multiple Linear Regression of CDC and CDC Incongruence on Patients' Depressed Mood

Predictor	Unstandardized coefficient		Standardized coefficient	t	P value	95% Confidence Interval	Adjusted R^2
	β	Std. error	β				
CDC total	-0.235	0.057	-0.203	-4.100	<.001	-0.348, -0.122	0.244
Open Communication	-0.593	0.141	-0.208	-4.220	<.001	-0.870, -0.317	0.246
Positive Outlook	-2.135	0.411	-0.265	-5.201	<.001	-2.943, -1.327	0.266
Spend Time Talking	-0.185	0.158	-0.059	-1.173	.242	-0.497, 0.126	0.207
Avoid Negative	0.632	0.174	0.181	3.640	<.001	0.290, 0.973	0.235
CDC incongruence total	2.667	1.356	0.098	1.967	.050	-0.001, 5.334	0.213
in Open Communication	1.281	0.978	0.066	1.310	.191	-0.644, 3.207	0.208
in Positive Outlook	4.059	0.934	0.217	4.346	<.001	2.221, 5.896	0.248
in Spend Time Talking	-0.548	0.741	-0.037	-0.739	.461	-2.007, 0.911	0.205
in Avoid Negative	1.261	0.787	0.080	1.602	.110	-0.288, 2.809	0.209

Note. CDC = Common Dyadic Coping. Models adjusted for age, years in relationship, household income, employment status, symptoms or side effects from therapy, any other diagnosed chronic illnesses, and whether receiving individual counseling.

Table 4.5

Multiple Linear Regression of CDC and CDC Incongruence on Patients' Anxiety

Predictor	Unstandardized coefficient		Standardized coefficient	t	P value	95% Confidence Interval	Adjusted R^2
	β	Std. error	β				
CDC total	-0.388	0.077	-0.265	-5.065	<.001	-0.538, -0.237	0.146
Open Communication	-0.994	0.187	-0.276	-5.318	<.001	-1.361, -0.626	0.153
Positive Outlook	-2.989	0.553	-0.294	-5.404	<.001	-4.078, -1.901	0.154
Spend Time Talking	-0.411	0.213	-0.103	-1.928	.055	-0.830, 0.008	0.088
Avoid Negative	0.974	0.233	0.222	4.182	<.001	0.516, 1.433	0.124
CDC incongruence total	3.705	1.833	0.108	2.021	.044	0.098, 7.311	0.089
in Open Communication	1.962	1.319	0.080	1.487	.138	-0.634, 4.558	0.084
in Positive Outlook	5.719	1.258	0.243	4.545	<.001	3.243, 8.194	0.132
in Spend Time Talking	-1.250	1.002	-0.067	-1.247	.213	-3.222, 0.722	0.082
in Avoid Negative	2.097	1.063	0.106	1.973	.049	0.006, 4.188	0.087

Note. CDC = Common Dyadic Coping. Models adjusted for age, years in relationship, household income, employment status, symptoms or side effects from therapy, any other diagnosed chronic illnesses, and whether receiving individual counseling.

Table 4.6

Multiple Linear Regression of CDC and CDC Incongruence on Spouses' Depressed mood

Predictor	Unstandardized coefficient		Standardized coefficient	t	P value	95% Confidence Interval	Adjusted R^2
	β	Std. error	β				
CDC total	-0.352	0.068	-0.268	-5.143	<.001	-0.487, -0.217	0.153
Open Communication	-0.854	0.166	-0.269	-5.148	<.001	-1.180, -0.528	0.150
Positive Outlook	-2.613	0.427	-0.315	-6.124	<.001	-3.452, -1.773	0.177
Spend Time Talking	-0.421	0.186	-0.122	-2.259	.025	-0.787, -0.054	0.096
Avoid Negative	0.693	0.198	0.186	3.498	<.001	0.303, 1.083	0.113
CDC incongruence total	4.153	1.347	0.165	3.084	.002	1.503, 6.802	0.109
in Open Communication	1.956	0.975	0.108	2.006	.046	0.037, 3.875	0.093
in Positive Outlook	3.397	0.917	0.197	3.707	<.001	1.594, 5.201	0.117
in Spend Time Talking	0.782	0.733	0.058	1.067	.287	-0.660, 2.224	0.085
in Avoid Negative	1.288	0.770	0.090	1.674	.095	-0.226, 2.803	0.087

Note. CDC = Common Dyadic Coping. Models adjusted for age, years in relationship, household income, employment status, and whether joined cancer support group.

Table 4.7

Multiple Linear Regression of CDC and CDC Incongruence on Spouses' Anxiety

Predictor	Unstandardized coefficient		Standardized coefficient	t	P value	95% Confidence Interval	Adjusted R^2
	β	Std. error	β				
CDC total	-0.521	0.081	-0.331	-6.400	<.001	-0.681, -0.361	0.152
Open Communication	-1.204	0.198	-0.318	-6.085	<.001	-1.594, -0.815	0.141
Positive Outlook	-3.608	0.507	-0.365	-7.114	<.001	-4.606, -2.610	0.172
Spend Time Talking	-0.688	0.223	-0.167	-3.082	.002	-1.128, -0.249	0.071
Avoid Negative	1.050	0.238	0.236	4.419	<.001	0.583, 1.518	0.096
CDC incongruence total	4.273	1.610	0.145	2.654	.008	1.105, 7.441	0.064
in Open Communication	3.015	1.143	0.144	2.639	.009	0.767, 5.263	0.064
in Positive Outlook	3.468	1.100	0.171	3.153	.002	1.304, 5.632	0.070
in Spend Time Talking	0.219	0.881	0.014	0.249	.803	-1.513, 1.952	0.044
in Avoid Negative	1.152	0.935	0.068	1.233	.219	-0.687, 2.991	0.046

Note. CDC = Common Dyadic Coping. Models adjusted for age, years in relationship, household income, employment status, and whether joined cancer support group.

Chapter 5: Synthesis Across Studies

Contributions of the Three Studies

To the author's knowledge, Study 1 is the most comprehensive review and concept analysis of human suffering since the work of Rodgers and Cowles (1997) and Best et al (2015). Rodgers and Cowles (1997) reviewed 56 articles from 1987 to 1994 without a limit on disease types; Best et al. (2015) analyzed 128 articles published between 1992 and 2012, only focusing on negative responses to suffering in cancer patients; whereas Study 1 included 172 articles published from 1940 to 2021 without a limit on types of illness. This study also, for the first time, provided a historic review of the extant definitions of suffering, and compared suffering with related and opposite concepts. The product of Study 2 was a new multi-dimensional measure of common dyadic coping with satisfactory face validity, structural validity, and acceptable internal consistency. Previously, the most commonly used measure of common dyadic coping was the five-item subscale in Dyadic Coping Inventory (DCI) (Bodenmann, 2008), with each item representing one positive type of common dyadic coping. The new measure developed in Study 2, CDC-C, is the first common dyadic coping measure that has a particular focus on inter-partner communication, and involves not only positive, but also negative types of common dyadic coping (i.e., avoid discussing negative thoughts and feelings). Study 3 added knowledge on how and which types of common dyadic coping and its congruence influence psychological suffering of both women diagnosed with early-stage breast cancer and their spouse caregivers. Study 3 also produced interesting findings that were new to the literature, such as couple's congruence in avoidance coping predicted women's lower distress, and spending time talking about breast cancer significantly reduced spouses' psychological suffering. All these findings deserve further investigation in future studies with more diverse populations and with larger sample sizes.

Implications for Health Care Practice

Study 1 identified critical antecedents and attributes of suffering that can inform health care practice for patients who are suffering. For instance, realizing suffering is subjective, health care providers may want to provide tailored therapeutic care based on each patient's particular needs. Realizing suffering is unspeakable, providers may consider encouraging patients' narrative by creating a safe space, using attentive, empathetic listening, or leveraging ancillary non-verbal tools such as mandala drawings to assist expression (Ivonin et al., 2013). Considering patients' sense of lacking control and meaninglessness in suffering, providers can help by encouraging accomplishing small tasks to remain control and facilitating patients' meaning making to alleviate suffering. Understanding suffering often occurs when the person's coping resources are depleted, providers may help by equipping patients with stronger coping skills and resources to improve their threshold of bearing external threats.

Evidence from Study 2 and 3 demonstrates the importance of couples' open communication and disclosure of both positive and negative thoughts and feelings to each other when coping with a shared stressor. Health care providers may want to help reduce couples' cancer-related depressed mood and anxiety by encouraging couple's open communication, their sharing a positive outlook, and discouraging couple's avoidance of expressing negative thoughts and feelings to each other. Couples' congruence in sharing a positive outlook on breast cancer could also be encouraged to reduce couple's psychological suffering.

Study Limitations and Implications for Future Research

Study 1 provides a conceptual foundation for future research on developing or refining a self-report measure of suffering in clinical screening and assessment. A valid and reliable measure of suffering is also in urgent need in future research investigating the predictors,

influencing factors, and potential outcomes of suffering, or testing hypothesized relationships in any theoretical frameworks of suffering. However, Study 1 only focused on suffering in adult patients in health care context. Children's and adolescents' suffering is a different area and needs a distinct and separate investigation. Social and environmental suffering induced by poverty, war, regional or ethnic conflicts, discrimination, social injustice, structural violence, natural disasters, and climate change were beyond the scope of Study 1 but are deserving future research. Additional research is also needed on the suffering of patients' caregivers, including health care providers and family members.

The new measure of common dyadic coping developed in Study 2 was restricted by the inherent limitations of secondary analysis and being able to only extract items from the self-reported questionnaire that was administered in the Helping Her Heal Study, the Mutuality and Interpersonal Sensitivity Scale (MIS). Recall that the main focus of the MIS was on couple's communication and was not envisioned as a measure of coping. Other components of common dyadic coping that were not reflected by MIS items were therefore not assessed, such as joint appraisal of the stressor and coping resources, joint problem-solving, and seeking social support. Future research needs to add additional items from these other domains to improve the content validity of this CDC scale. Future research is also needed to test the predictive validity of this scale. Study 3 revealed relationships between common dyadic coping, congruence in common dyadic coping, and psychological suffering in couples dealing with early-stage breast cancer. However, the study was cross-sectional, and the sample was dominated by White, middle-aged, highly educated, and well-off heterosexual couples in long-term marriages thereby limiting the generalizability of the study findings. Future research should include more diverse populations and use longitudinal design to test the proposed model over time.

References

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