

**Couples' Process of Becoming Change Agents in Caring for Daughters Living with
Eating Disorders**

by

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ABSTRACT

While a growing body of literature describes the experiences of parents, there is little known about couples' relationships while supporting their daughters living with eating disorders. In this study, we explored five couple relationships using the grounded theory method. A substantive theory of *couples becoming change agents* emerged that explains diverse adjustments in couples' relationships while supporting their ill daughters. As couples become change agents, they rely on the pathways of reflecting, coping, and strengthening resilience to move through stages of surviving the initial period, juggling responsibilities, and expanding supportive roles. At each stage, couples use coping strategies and reflect on the effectiveness of their actions as individuals and as couples, which strengthens their resilience and promotes change for their ill daughters. They later expand their support by becoming change agents within their families and communities. Advocacy by couples points to the need for further education and resources to support couples in caring for children experiencing eating disorders.

Keywords: couples, relationships, support, eating disorders, reflection, coping, resilience, grounded theory

DEDICATION

This thesis is dedicated to my mother, Mary, who continues to give me inspiration and insight into the profession of nursing. It is she who encouraged me to take the MN program, and gave me constant support throughout the process. Without her love, I would not be the person, or nurse, that I am today. I strive to become the compassionate example of nursing she has been over the last 39 years.

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Table of Contents

ABSTRACT	ii
DEDICATION	iii
ACKNOWLEDGEMENTS	iv
Table of Contents	v
List of Figures	vi
List of Symbols, Nomenclature or Abbreviations.....	vii
Chapter 1: Introduction	1
References	6
Chapter 2: Couples' Process of Becoming Change Agents in Caring for Daughters Living with Eating Disorders	19
References	64
Chapter 3: General Discussions and Conclusions.....	98
References	102
Appendix A: Eating Disorders Criteria DSM 5 – Diagnostic and Statistical Manual of Mental Disorders 5 th Edition	104
References	108
Appendix B: Letter to Self	110
Curriculum Vitae	

List of Figures

Figure 1 - Couples Process of Becoming Change Agents in Caring for Daughters Living with Eating Disorders	page 33
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List of Symbols, Nomenclature or Abbreviations

Appendix A: Eating Disorders Criteria DSM 5 – Diagnostic and Statistical Manual of Mental Disorders 5 th Edition	pages 95-96
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Chapter 1: Introduction

Eating disorders are complex health problems that affect millions of individuals worldwide, regardless of: (a) socioeconomic status (Lee et al., 2013; Mitchison, Hay, Slewa-Younan, & Mond, 2014); (b) culture (Hoste, Hewell, & Le Grange, 2007; Lee et al., 2013; Podar & Allik, 2009; Solmi, F., Hotopf, Hatch, Treasure, & Micali, 2015); (c) religion (Buser, Kearney, & Buser, 2015; Latzer et al., 2015); (d) sex (Harris & Cumella, 2006; Lee et al., 2013; Mitchison et al., 2014; Smith et al., 2017; Vo, Lau, & Rubinstein, 2016); (e) age (Conceicao, Gomes, Vaz, Pinto-Bastos, & Machado, 2017; Harris & Cumella, 2006; Mitchison et al., 2014); or (f) race (Burke et al., 2017; Hoste et al., 2007; Sala, Reyes-Rodriguez, Bulik, & Bardone-Cone, 2013). Although eating disorders affect many populations, they are primarily found in females during adolescence and young adulthood (Hoste et al., 2007; Jaite, Hoffmann, Glaeske, & Bachmann, 2013; Nagl et al., 2016; Pohjolainen et al., 2016; Sala et al., 2013). In Canada, a study of 3,043 adolescents using DSM 5 criteria (Appendix A) found that 3.7% of participants met the criteria for anorexia nervosa, bulimia nervosa, or binge eating disorder (Flament et al., 2015). The concentration of eating disorders in this age group means parents are often involved in accessing and engaging in services (Girz, Robinson, Foroghe, Jasper, & Boachie, 2013; Henderson et al., 2014; Mansson, Parling, & Swenne, 2016).

Parents are troubled by the effects of the eating disorder on their child's immediate health status (Whitney et al., 2005). Most disturbingly, eating disorders have the highest mortality rate of any mental illness, reported to be between 6-20% (Arcelus et al., 2011; Crow et al., 2009; Franko et al., 2013; Hoang, Goldacre, & James, 2014;

Suokas et al., 2013). Medical complications, such as cardiac compromise and suicide account for at least 60% of these deaths (Fichter & Quadflieg, 2016; Westmoreland, Krantz, & Mehler, 2016). Eating disorder mortality rates vary between studies due to different samples being studied over various time periods and may even exceed those that are reported in the literature (Arcelus et al., 2011). The cause of death may not include the diagnosis of eating disorders that are directly related to the manner of the death, such as suicide (Arcelus et al., 2011), or as physical complications of the illness including organ failure (Fichter & Quadflieg, 2016; Harris & Cumella, 2006), cardiac complications (Attia & Walsh, 2009; Mehler, Kratz, Sachs, 2015; Trent et al., 2013; Westmoreland et al., 2016), gastrointestinal bleeding (Westmoreland et al., 2016), and malnutrition (Harris & Cumella, 2006; Westmoreland et al., 2016).

In addition, parents need to manage their affected children's comorbid mental health issues and potentially irreversible long-term physical complications. Comorbid mental health concerns include depression (Attia & Walsh, 2009; Herpertz-Dahlmann, Dempfle, Konrad, Klasen, & Ravens-Sieberer, 2015; Yao, Kuja-Halkola, & Thornton, 2016), anxiety disorders (Attia & Walsh, 2009; Bühren et al., 2014; Degortes, Zanetti, Tenconi, Santonastaso, & Favaro, 2014; Herpertz-Dahlmann et al., 2015, Yao et al., 2016), post-traumatic stress disorder or trauma (Forman-Hoffman, Mengeling, Booth, Torner, & Sadler, 2012; Stephens & Wilke, 2016; Trottier, Wonderlich, Monson, Crosby, & Olmsted, 2016), and substance abuse (Mann et al., 2014; Yao et al., 2016). Associated physical complications are osteopenia (Pinzon & Beimers, 2005), and infertility and other reproductive abnormalities (Linna et al., 2013; Pinzon & Beimers, 2005), such as amenorrhea (Berner, Feig, Witt, & Lowe, 2017). Clearly, eating

disorders are serious health conditions with longstanding effects on overall well-being and quality of life (Ackard et al., 2014; Jenkins, Hoste, Meyer, & Blissett, 2011; Tall, 2009; Wagner, Stefano, Cicero, Latner, & Mond, 2016).

The health of parents caring for children living with eating disorders (Laghi et al., 2017; Ma, 2011; McCormack & McCann, 2015; Patel, Shafer, Brown, Bulik, & Zucker, 2014; Raenker et al., 2013; Svensson, Nilsson, Levi, & Suarez, 2013; Winn et al., 2007) may be affected by high levels of stress (Fox et al., 2017; McCormack & McCann, 2015; Perkins, Winn, Murray, Murphy, Schmidt, 2004; Svensson et al., 2013; Zabala, MacDonald, & Treasure, 2009) and perceived burden (Coomber & King, 2013; Martin et al., 2011; Patel et al., 2014; Zabala et al., 2009) while responding to their child's changing health needs. While the specific impacts on the health of parents as individuals has been studied (e.g. Horesh, Sommerfeld, Zubery, & Zalsman, 2015; Laghi et al., 2017; Lantzouni, Cox, Salvator, & Crosby, 2015; McCormack & McCann, 2015; Raenker, et al., 2013; Svensson et al., 2013; Tuval-Mashiach, Hasson-Ohayon, & Ilan, 2013; Weaver, 2012; Whitney et al., 2005), there is limited knowledge about the impact on parents' interpersonal relationships as couples when caring for their children living with eating disorders. Indeed, when couples have been studied as a unit, their perspectives have been analyzed using quantitative scales (Espina, DeAlda, & Ortego, 2003; Latzer et al., 2009; Strober, 1981), a methodology which restricts the understanding of the context of couples' experiences caring for children living with eating disorders. Drawing on studies of couples' interactions caring for children experiencing other chronic conditions (e.g., autism spectrum disorder), the varied levels

of stress and relationship quality reported have depended on perceptions of spousal support (Machado da Silva et al., 2010; Saini et al., 2015; Pao & Bosk, 2011).

Collaboration between nurses and families is considered vital in treating eating disorders and restoring positive family life (Silber, Lyster-Mensch, & DuVal, 2011). Nurses play a significant role in eating disorder care (Carter, Webb, Findlay, Grant, & Van Blvderveen, 2012; Davey, Arcelus, Munir, 2013; Kong, 2005; Silber et al., 2011), and have identified concerns regarding inconsistencies in care (Carter et al., 2012; Harkin, Maxwell, Hainline, Pollack, & Roberts, 2017), difficulties managing complex family dynamics (Harkin et al., 2017), and uncertainty of how to respond to clients and families (Harkin et al., 2017). In the literature reviewed, it is unclear what nursing knowledge guides practice in relation to interacting with couples caring for their children living with eating disorders.

Therefore, the purpose of this thesis research project was to explore care issues from the perspectives of couples. The initial research question was “How do couples manage caring for daughters living with eating disorders?” A qualitative exploratory study would answer this question that is relevant to my nursing practice in a specialized outpatient eating disorders clinic. Although I have learned and applied nursing theories to my practice (e.g. strengths-based nursing care), I have directly worked with many couples who have children living with eating disorders without having a specific theory related to couples’ needs. A more specific theory based on couples’ perspectives was sought to enhance effective care based on the needs identified by the population. I also function as a Resource Nurse sharing knowledge to build staff capacity about evidence-

informed eating disorders practice. In this way, this research would also help inform my practice and the practice of other nurses, physicians, and allied staff.

I was the principle investigator of this study and the primary author of the article “Couples’ Process of Becoming Change Agents in Caring for Daughters Living with Eating Disorders” (Chapter 2). My supervisor (Dr. Kate Weaver) and committee member (Dr. Grace Getty) were involved as the second and third investigators and authors. Dr. Weaver had previously done a study of 29 New Brunswick parents who cared for daughters living with eating disorders. A sub-set of that data was the 5 couples who consented to be part of this study. The need for this study was collectively identified by Dr. Weaver and I during my MN independent study course work. All three investigators determined that the qualitative method of grounded theory would best answer the research question. I did the data analysis in collaboration with Dr. Weaver and Dr. Getty. I prepared the article with significant input and guidance from Dr. Weaver and Dr. Getty.

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Chapter 2: Couples' Process of Becoming Change Agents in Caring for Daughters Living with Eating Disorders

Eating disorders affect the whole family, especially, parents as individuals and as couples (Ma, 2011; McCormack & McCann, 2015; Patel, Shafer, Brown, Bulik, & Zucker, 2014; Raenker et al., 2013; Svensson, Nilsson, Levi, & Suarez, 2013; Winn et al., 2007). While there is no doubt that eating disorders significantly influence the health, overall well-being, and quality of life of those affected (Ackard et al., 2014; Jenkins, Hoste, Meyer, & Blissett, 2011; Tall, 2009; Wagner, Stefano, Cicero, Latner, & Mond, 2016), there is little known about such influence on couples' relationships and well-being while caring for their children with eating disorders. In much of the literature, the experiences of parents as mothers and fathers have been analyzed separately (Hillege, Beale, & McMaster, 2006; Honey & Halse, 2006; Horesh, Sommerfeld, Zubery, & Zalsman, 2015; Laghi et al., 2016; Lantzouni, Cox, Salvator, & Crosby, 2015; McCormack & McCann, 2015; Perkins, Winn, Murray, Murphy, & Schmidt, 2004; Raenker, et al., 2013; Svensson et al., 2013; Trecartin, 2010; Tuval-Mashiach, Hasson-Ohayon, & Ilan, 2013; Weaver, 2012; Whitney et al., 2005), and there is little research that focuses on couples in the context of caring for children living with eating disorders. This lack of understanding of couples' experiences and needs limit the ability of professionals to provide comprehensive family-oriented care.

To address this knowledge gap, the stories and experiences of couples whose children are living with eating disorders were explored. Access was granted to the data of a larger qualitative study of New Brunswick parents who cared for daughters living with eating disorders (Weaver, 2012). From this larger sample, five couples agreed to

participate in this study. Secondary analysis of these couples' interview data involved using a grounded theory method. In this article, we describe literature relative to eating disorders and couples' experiences and our use of grounded theory methodology, as well as our original midrange theory (*couples becoming change agents*) that emerged from the data.

Literature Review

A basic literature review was done to sensitize the student researcher (primary author) to what is known about the issue. To locate literature regarding couples' interactions while caring for children living with eating disorders, combined keywords *eating disorders, DSM 5, caregiv*, mother or father, couples, parents, daughter, ill child, anorexia nervosa, bulimia nervosa, and chronic illness* were searched in CINAHL, Health Source: Academic Edition, PsychInfo, ProQuest Nursing and Allied Health Source, PubMed, Google Scholar, and Sociological Abstracts. Over 300 full-text scholarly articles published between 1958 and 2017 were reviewed. In addition, manual searches of these articles were conducted to locate further relevant literature. This body of literature explored the parent-child dyad (Bonne et al., 2003; Ketisch, Jones, Mirsalimi, Casey, & Milton, 2014; Minuchin et al., 1978) and family dynamics (Bonne et al., 2003; Folse & Krawzak, 2013; Gillet, Harper, Larson, Berrett, & Hardman, 2009; Ketisch et al., 2014; Kluck et al., 2014; Laghi et al., 2016; Marcos, Sebastian, Aubalat, Ausina, & Treasure, 2013). However, literature that focused on the relationships within couples who had children with eating disorders was sparse. To specifically focus on couples' relationships, we reviewed the theoretical underpinnings of couples' dynamics, couples' relationships within families, and the cultural context in which these

relationships are embedded. The experiences of couples parenting healthy children, chronically ill children, and children living with eating disorders were also explored. The literature continued to be sampled throughout data analysis.

Theoretical Underpinnings of Couples' Dynamics

Couples' relationships were noted to play a significant role in the health of couples themselves, their children, and their families (Coleman & Glenn, 2010; Kiecolt-Glaser & Wilson, 2017; Schofield, Mumford, Jurkovic, Jurkovic, & Bickerdike, 2012). For that reason, we explored the literature related to couples' interactions, i.e. attachment theory (Bowlby, 1973; Bowlby, 1988; Dalgleish et al., 2015; Fraley, 2010; Hazan & Shaver, 1987) and social exchange theory (Blau, 2009; Nakonezny & Denton, 2008; Thibaut & Kelley, 1959; Paat, 2013).

Attachment theory. Beginning with Bowlby in the 1950s, research focused on the attachment between children and their parents (Bowlby, 1958). Bowlby observed that infants look for safety, intimacy, and protection (Bowlby, 1973). Over time, the study of attachment was extended to include the attachment of adults in romantic relationships (Dalgleish et al., 2015; Fraley, 2010; Hazan & Shaver, 1987; McWilliams, 2004). Attachment, defined as a strong, loving, emotional bond (Cuenca-Montesino, Grana, & O'Leary, 2015; Frost & Gola, 2015; Harris et al., 2016; Sprecher & Fehr, 2010) has been associated with a sense of security and safety (Bowlby, 1973; Dalgleish et al., 2015; Mikulincer & Shaver, 2007). The attachment within couples includes their love (Cuenca-Montesino et al., 2015; Graham, 2011; Harris et al., 2016), trust (Frost & Gola, 2015), and commitment toward one another (Frost & Gola, 2015; Graham, 2011). The strength of the attachment was found to be influenced by the individual partners'

coping strategies (Bodenmann, Bradbury, & Pihet, 2009; Falconier, Jackson, Hilpert, & Bodenmann, 2015; Levesque et al., 2014; Hinneken, Lemmens, Vanhee, & Verhofstad, 2016) which included their ability to communicate emotional responses (Falconier et al., 2015; Hinneken et al., 2016; Ledermann, Bodenmann, Rudaz, & Bradbury, 2010) and feelings of empathy (Levesque, Lafontaine, Caron, Flesch, & Bjornson, 2014).

Attachment was further enhanced by partners' friendship (Harris et al., 2016) or time spent together (Frost & Gola, 2015), ability to adapt to change (Harris et al., 2016), and shared values such as gratitude and desire to meet partners' needs (Kubacka, Finkenauer, Rusbult, & Keijsers, 2011).

Recently, research on attachment has focused on partners' sense of "we-ness" or the social identity of the couple instead of each individual (Ahmad et al., 2017; Gildersleeve, Singer, Skerrett, & Wein, 2017; Strong, Jong, & Merritt, 2014). This focus includes respect (Gildersleeve et al., 2017), spousal social support or working together to provide information, practical help, and emotional support to each other (Ahmad et al., 2017; Gildersleeve et al., 2017; Hinneken, et al., 2016; Skerrett, 2016), and overall relationship satisfaction (Hinneken, et al., 2016). "We-ness" as part of secure attachment has been found to provide a sound foundation for the health of couples and their families (Ahmad et al., 2017; Galdiolo et al., 2016; Skerrett, 2016).

Social exchange theory. Premised on the belief that couples are motivated by positive attributes such as trust and commitment, social exchange theory contends that couples' relationships depend on their perceptions of the equity of goods and services exchanged (Blau, 2009; Frost & Gola, 2015; Nakonezny & Denton, 2008; Thibaut & Kelley, 1959). Individual partners consider the cost and rewards of the relationship in

comparison to what they believe they deserve (McInnes Miller & Bermudez, 2004; Nakonezny & Denton, 2008; Thibaut & Kelley, 1959). McClintock (2014) explained that when one partner contributes more of an asset, the other may compensate by making different contributions. A partner who perceives fewer benefits of the relationship may feel less satisfied, which could potentially lead to changing dynamics or the end of the relationship (Nakonezny & Denton, 2008; Paat, 2013; Wright & Aquilino, 1998).

Couples' Relationships within Families

Couples' relationships and parenting styles were noted to play a significant role within family structures (Adamson, 2010; Ali, 2015; Coleman & Glenn, 2010; Floyd, Gilliom, & Costigan, 1998; Lobera, Rois, & Casals, 2011; Paat, 2013; Salvatore, Kuo, Steele, Simpson, & Collins, 2011; Schofield, Mumford, Jurkovic, Jurkovic, & Bickerdike, 2012; Wu, Hou, & Schimmele, 2008). These couple relationships involved their alliance, which included communicating about shared goals and values related to parenting (Floyd et al., 1998) and working together to implement the chosen approach (Ali, 2015). Such alliance contributed to couples' marital satisfaction (Kolak & Volling, 2007; Morrill, Hines, Mahmood, & Cordova, 2010) and their children's emotional-social development (Altenburger, Lang, Schoppe-Sullivan, Kamp Dush, & Johnson, 2017) through overcoming challenges of rewarding and disciplining their children (Adamsons, 2010; Jang & Ryu, 2016; McKinney, Milone, & Renk, 2011) and helping the children regulate their emotions and behaviours (Salvatore et al., 2011; Wu et al., 2008). It has been shown that how children perceive themselves and interact with others (Campbell & Marshall, 2011) is influenced by how couples model effective

communication, emotional expression, and boundary setting (Ali, 2015; Altenburger et al., 2017) and provide protection, safety, and intimacy within the parent-child relationships (Ali, 2015; Bowlby, 1973; Floyd et al., 1998; Salvatore et al., 2011).

Couples' experiences caring for healthy children. As children grow into adolescents, their developmental tasks of asserting independence and developing a sense of individuality accelerates (Abebe, Torgersen, Lien, Hafstad, & von Soest, 2014; APA, 2002). Adolescents' increasing attachment to their peers challenges parental roles (Allen & Miga, 2010; Gorrese & Ruggieri, 2012; Hadiwijaya et al., 2017). The upheaval in family dynamics over authority, autonomy, responsibilities, and appropriate behaviours creates increased stress for the parent couple (Abrams, 2015; Anthony, Williams, & LeCroy, 2014; Hadiwijaya, Klimstra, Vermunt, Branje, & Meeus, 2017; Jagers et al., 2015; Reyes & Ohannessian, 2016; Smetana, 2011). Couples can negotiate this difficult period by providing a consistent approach through joint involvement in care and decision making during their adolescents' development (Riina & McHale, 2014).

Couples' experiences caring for ill children. Chronic illness complicates child development (Lipstein, Muething, Dodds, & Britto, 2013; Machado da Silva, Jacob, & Nascimento, 2010; Pao & Bosk, 2011) with increased demands on both couple and parent-child relationships. For example, couples caring for chronically ill children reported adjusting roles to meet their children's needs (Machado da Silva et al., 2010; Pelentsov, Fielder, Laws, & Esterman, 2016; Smith, Cheater, & Bekker, 2013) based on individual partners' coping (Machado da Silva et al., 2010) and couples' communication with each other (Machado da Silva et al., 2010). Other factors such as grief (George,

Vickers, Wilkies, & Barton, 2006; Richardson, Cobham, Murray, & McDermott, 2011), level of stress (Aldridge, 2008; Alzahrani, Fallata, Alabdulwahab, Alsafi, & Bashawri, 2017; Garro, Thurman, Kerwin, & Ducette, 2005; Smith et al., 2013; Tong, Lowe, Sainsbury, & Craig, 2010), feelings of social isolation (Aldridge, 2008; Pelentsov et al., 2016), and difficulties dealing with health professionals (George et al., 2006; Pelentsov et al., 2016; Smith et al., 2013) were often reported when caring for an ill child.

Couples' relationship satisfaction and ability to cope with stress were found to be influenced by their perceptions of the support received from each other (Donato et al., 2015; Kimmes, Edwards, Wetchler, & Bercik, 2014) and their ability to focus on positive aspects of the situation (Machado Silva-Rodrigues, Pan, Pacciulio Spostito, de Andrade Alvarenga, & Nascimento, 2016).

Couples' experiences caring for children living with eating disorders. Some couples caring for children with eating disorders reported significantly higher levels of distress within their relationships (Espina, DeAlda, & Ortego, 2003) and lower marital quality as measured by factors such as personality issues, egalitarian roles, and conflict resolution when compared to controls (Latzer et al., 2009). Unfortunately, the lower marital quality was also clear to their ill daughters, with daughters perceiving lower marital quality than their mothers or fathers (Latzer et al., 2009). Higher marital quality was associated with better parent-child relationships and lower levels of eating disorder psychopathology (Latzer et al., 2009). Both studies used quantitative scales to measure couples' coping (adjustment), levels of distress, and marital quality. The studies did not specify health status of the controls (Latzer et al., 2009) or what pathologies were present in controls (Espina et al., 2003). Given that some of the controls were likely

caring for healthy children, we expected that differences in levels of distress and marital quality would be present.

In contrast, other parents reported that their child's illness had not affected their couple relationship (Ma, 2011). Given that couples have often suggested their relationships were either strengthened or strained when caring for an ill child (Pelentsov et al., 2016), it is not surprising that couples would express varied views on their relationships when caring for children experiencing eating disorders. Within the body of literature of caring for children with eating disorders, parents' experiences were influenced by the perceived strain on their marriage (Whitney et al., 2005), length of their child's illness (Patel et al., 2014), level of education (Padierna et al., 2013), and divorce status (Padierna et al., 2013). Individual parents and couples reported the following coping strategies as helpful: (a) separating the eating disorder from their child (Honey & Halse, 2006; Weaver, Martin-McDonald, & Spiers, 2016); (b) communicating with each other about the eating disorder (Hopf, Le Grange, Moessner, & Bauer, 2013; Svensson et al., 2013); (c) accepting the situation (Svensson et al., 2013); (d) choosing to think in a hopeful and optimistic manner (Weaver, 2012; Whitney et al., 2005); and (e) using self-distraction techniques of going to work (Weaver, 2012), doing physical activity (Whitney et al., 2005), and taking time to rest (Svensson et al., 2013).

Cultural Contexts

Culture involves learned behaviours such as language, religion, traditions, and beliefs held by persons within social groups such as families, communities, and societies (O'Neil, 2006; Zimmermann, 2017). Dynamic and fluid, culture evolves over time (O'Neil, 2006, Spencer-Oatey, 2012). Consideration of historical and socio-cultural

differences among people such as ethnic origins, gender roles, or religion were suggested to avoid stigmatizing or stereotyping caregivers and persons living with eating disorders (Chan & Ma, 2005; Doumit, et al., 2017; Gonzales, et al., 2015; Ma, 2011). Three social determinants of health (Public Health Agency of Canada, 2011), cultural influences, gender norms, and stigma (within social support networks) were found to influence couples' relationships (Fraser & Warr, 2009; Friedemann & Buckwalter, 2014; Gaunt, 2013; Laws, 2004; Moller, Gudde, Folden, Linaker, 2009) when caring for daughters living with eating disorders (Ma, 2011; Whitney, Haigh, Weinman, & Treasure, 2007). These determinants affected how couples viewed many aspects of their lives including access to and meaning of food (Chan & Ma, 2002; Manochio-Pina, Dos Santos, Dressler, & Ribeiro, 2015), desired body shape or size (Chan & Ma, 2005; Kadish, 2012; Ma, 2011), caregiving roles (McNeill et al., 2014; Montgomery, Chaviano, Rayburn, & McWey, 2016), and perceptions of themselves (Whitney et al., 2005).

Gender roles in caring. Gender refers to a range of gender identities beyond the binary female and male sex categories (World Health Organization [WHO], 2017). Families, communities, and societies socially construct gender norms and expectations based on biological sex (WHO, 2017). Couples' perceptions of gender norms influence the care they provide to their children (McNeill et al., 2014; Montgomery et al., 2016). In an American case study, Dickerson (2013) reported that the husband found it difficult to describe himself as compassionate while the wife found it hard to identify herself as courageous. This was consistent with the prevailing social constructs of masculinity and femininity in the Western world wherein women have been expected to be submissive,

nurturing, emotional, and expressive, while men have been expected to be dominant, competitive, and rational decision-makers (Lindsey, 2016; Stets & Burke, 2000).

Recently, data from 4000 men and women from over 20 countries showed that women were becoming better-educated, more involved in making economic decisions, and working to redefine their roles within their homes and societies regardless of culture or location (World Bank, 2013). Accordingly, the gender roles and societal expectations of men and women have evolved to be more inclusive of roles outside of traditional expectations and practices (Fulcher, et al., 2015; Lindsey, 2016; Sweeting, Bhaskar, Benzeval, Popham, & Hunt, 2013; World Bank, 2013; Wang, Parker, & Taylor, 2013).

Despite changed views of caregiving activities, researchers suggest that traditional gender roles continue to affect caregiving experiences and expectations (Fraser & Warr, 2009; Friedemann & Buckwalter, 2014; Gaunt, 2013; Laws, 2004; Moller et al., 2009). To illustrate, Gaunt (2013) noted that “traditional [Western] individuals tended to evaluate the primary caregiving mother and the breadwinning father more favorably than the male caregiver and female breadwinner, [while] egalitarians tended to evaluate the primary caregiving father and the breadwinning mother more favorably” (p. 19). Affirming the importance of mothers’ traditional caregiving role, Halvorsen and Heyerdahl (2007) reported both mothers and fathers rated mothers’ (compared to fathers’) support as “somewhat more important” in promoting their child’s eating disorder recovery (p. 637).

We found less literature about fathers’ (compared to mothers’) experiences caring for children living with eating disorders. Some daughters with eating disorders have reported that expressions of caring (Horesh et al., 2015) and love (Woods, 2004)

from their fathers helped them recover. Using the fathers' interviews from the same dataset as this current study, Trecartin (2010) found that fathers initially struggled to understand their children's illness. These fathers moved through a trajectory from feeling stress, guilt, and regret towards compassion, and finally to building an understanding relationship with their daughters (Trecartin, 2010). The influence of both parents has been deemed important in helping children with eating disorders work towards and maintain recovery (Girz, Robinson, Foroghe, Jasper, & Boachie, 2013; Mond et al., 2007; Woods, 2004).

Stigma. Eating disorders are highly stigmatized conditions in our society (Ebnetter, Latner, & O'Brien, 2011; McLean et al., 2014; Shidhaye & Kermode, 2012; Thornicroft, Rose, Kassam, & Satorius, 2007; Whitney et al., 2007; Zwickert & Rieger, 2013). Stigmatizing behaviours, such as bullying, reflect negative attitudes and/or judgements towards persons based on characteristics or attributes they possess (Goffman, 1963; Thornicraft et al., 2007). This includes the idea that eating disorders are a moral flaw (Ebnetter, Latner, & O'Brien, 2011). Caregivers (not specified as couples) have been found to feel emotionally distressed because of their perceived stigma (McMaster, Beale, Hillege, & Nagl, 2004; Whitney et al., 2007). Although the literature is lacking, couples may experience, perceive, or internalize stigma (Brohan, Slade, Clement, & Thornicroft, 2010) and blame themselves for their child's eating disorder (Whitney et al., 2005). Such feelings of guilt were magnified by perceived blame from health professionals (McMaster et al., 2004; Minuchin, Rosman, & Baker, 1978). This blame was primarily placed on mothers within the couple relationship (McMaster et al., 2004), and likely reflected Western societal views of mothers' roles in

caregiving. In fact, researchers have associated parents' comments about weight and/or shape (Cordero & Israel, 2009), body dissatisfaction and drive for thinness (Canals et al., 2009), and inability to control emotions such as hostility or negativity (Gale, Cluett, & Laver-Bradbury, 2013; Ravi, Forsberg, Fitzpatrick, & Lock, 2008; Weisbuch et al., 2011), overprotectiveness (Abebe et al., 2014; Gale et al., 2013), and perfectionism (Gale et al., 2013) to having a child with an eating disorder.

These viewpoints may blame parents without consideration of the many known factors that contribute to eating disorder development including the child's personality traits such as perfectionism (Culbert, Racine, & Klump, 2015; von Lojewski & Abraham, 2014), psychological factors such as self-esteem (Petrie, Greenleaf, Reel, & Carter, 2009), and changes in body composition related to the onset of puberty (Klump, 2013; Tall, 2009). External factors such as media portrayals of ideal bodies (Culbert et al., 2015; Tall, 2009), significant life stressors (Hardaway, Crowley, Bulik, & Kash, 2015; Mitchison & Hay, 2014) such as parents' divorce (Tall, 2009), and social factors such as interpersonal anxiety (von Lojewski & Abraham, 2014) and bullying (Mitchison & Hay, 2014) also influence eating disorder development. Given that researchers had suggested parental factors cause or influence eating disorder development, health professionals may continue to view parents of children with eating disorders negatively and perpetuate the perceived blame and stigma that parents, particularly mothers, experience.

In the literature review, a trend of involving family members in treatment was noted (Bass, 2015; Chen et al., 2010; Fox, Dean, & Whittlesea, 2017; Henderson et al., 2014; Hildebrant, Bacow, Markella, & Loeb, 2012; Lock & Le Grange, 2005; Lock &

Le Grange, 2013; Selvini-Palazolli, 1978; Whitney & Eisler, 2005). Increased education and skill-building for parents helped reduce perceived burden (Goodier et al., 2014; Hibbs, Rhind, Leppanen, & Treasure, 2015), increase insight into the illness (Whitney et al., 2012), and raise caregiving efficacy while reducing levels of distress (Goodier et al., 2014). These positive results warrant further research into couples' parental roles in eating disorders care.

Summary of Literature Reviewed

The literature about couples' dynamics, couples' relationships within families, and cultural contexts lacks current research considering couples' relationships while caring for children living with eating disorders. Couples' relationships have been studied using quantitative scales, but the process couples go through is unknown. Our qualitative study aimed to fill this gap in the literature by providing more information about couples' relationships when caring for children living with eating disorders.

Method

Grounded theory was chosen to enable the emergence of a theory that would explain the diverse adjustments in couples' relationships while caring for daughters living with eating disorders. Grounded theory is rooted in symbolic interactionism, the theory that verbal and non-verbal interactions create, explain, and change meaning in peoples' lives (Aldiabat & Le Navenec, 2011; Baker, Wuest, & Stern, 1992; Blumer & Morrione, 2004; Chen & Boore, 2009; Moore, 2009). For example, the meaning of the word love might change after marriage. This change is influenced by commitment and trust that evolves over time within married couples' relationships (Harris et al., 2016). Symbolic interactionism is applied to research when the researchers intend to identify

the process by which meaning is developed and represented in human interactions (Gallant & Kleinman, 1983; Hunter, Murphy, Grealish, Casey, & Keady, 2011a; Moore, 2009; Schwandt, 1994). This is similar to identifying the basic social psychological process (e.g., couples becoming change agents) in classic grounded theory research. We used grounded theory principles to develop a theory that fit the data and had meaning to the study participants.

Participants. The data used in this research study were previously collected by the second author for her study of parents' stories caring for children with eating disorders (Weaver, 2012). The original data, resulting from a reflective narrative interview process, were expressions of the participants' perspectives and experiences and therefore could be re-examined through grounded theory principles. Five out of seven couples consented for re-analysis of their data by the primary author. These couples were middle aged (44-63 years), well educated (most participants had a college or university degree), and had steady incomes. Four of the couples were married and resided together, while the other couple was divorced at the time of the interviews. One of the couples was of Acadian French Heritage. All couples had daughters who were 11-22 years old when diagnosed with anorexia nervosa or bulimia nervosa.

Ethical considerations. Ethics review was conducted by the University of New Brunswick Research Ethics Board under file REB 2014-142. Although consent is not a usual requirement of secondary analysis when using anonymized data (Government of Canada, 2014), potential participants were informed about the study by the second author and had the opportunity to discuss any questions or concerns with the researchers prior to consenting to having their data included in the data set for this current study.

All participants received a midterm summary of the findings. Two participants replied and confirmed the relevance of the emerging theory.

Grounded Theory Analysis

Classic grounded theory (Glaser & Strauss, 1967; Glaser, 1978; Glaser 1998) informed the data analysis process, which included analysis through open, selective, and theoretical coding, memoing, sorting, and theoretical sampling (Glaser, 1978; Glaser 1998; Glaser & Strauss, 1967). Open and selective coding are also referred to as substantive coding (Glaser, 1978).

Open coding. Open coding involved “coding the data in every way possible” (Glaser, 1978, p. 56). The primary author did line by line coding of the 10 interviews by reading each line of data and breaking down different instances into “analytical pieces” or codes that represented the emerging ideas and categories (Glaser, 1978, p. 56). In this study, open codes included blaming, communicating, changing relationships, and seeking support. As the open codes emerged, they were compared to each other and clustered into categories of data. Emerging categories were constantly compared to each other and to incoming codes. As Glaser suggested (1978), the primary author continually questioned “what is happening in the data?” (p. 57). Categories refined through constant comparison included surviving the initial period, juggling responsibilities, and expanding supportive roles.

Selective coding. Selective coding involved focusing on one core variable, which was central, recurrent in the data, and related to the other emerging categories (Glaser, 1978). The primary author continually considered the other data in relation to

the core variable (Glaser, 1978). This process of selective coding led to the discovery of the basic social psychological process of couples becoming change agents.

Theoretical coding. Theoretical codes are linkages that bring meaning to substantive codes by exploring how the substantive codes interact with each other (Glaser, 1978; Glaser, 1998). Theoretical codes consist of coding families (e.g., the Six C's family, the identity-self family, and models) that enable the researcher to classify and connect the substantive codes within the emerging theory (Glaser, 1978). The Six C's coding family includes contexts, consequences, and conditions (Glaser, 1978). An example of a condition that influenced the process of couples becoming change agents was their coping ability. A consequence of perceiving the urgency of their daughters' health condition was to begin accessing help. Contextual theoretical codes included couples' prior coping skills and their social support. The identity-self coding family (Glaser, 1978) relates to their transformation and self-growth. For example, couples transformed from harshly evaluating their self-worth to recognizing their strengths and abilities. We created a model (Figure 1), which is another theoretical coding family that provided a visual representation of the substantive theory (Glaser, 1978).

Theoretical saturation and sampling. Theoretical saturation occurs when “no additional data are being found whereby the [researcher] can develop properties of the category” (Glaser & Strauss, 1967, p. 61). Theoretical saturation is unlikely with a small sample size (Morse, 2015), such as the five couples in this study. However, in the emerging theory no new categories emerged from the interview data. In this study, two sub-stages (i.e., pre-discovery and sense of urgency) did not reach theoretical saturation. In attempting to saturate the categories, theoretical sampling of the literature began as

another source of data to move towards theoretical completeness. We theoretically sampled literature on change agents, couples' and parents' coping, and resilience while caring for an ill child. This literature strengthened the basic social psychological process and categories.

Memoing. Throughout coding and analysis, the primary author memoed. This involved writing up any theoretical ideas about the codes and their relationships (Glaser, 1978). Some short memos written by the primary author included “Gender roles appear to influence the social exchanges between partners – in some instances traditional roles impact the division of responsibilities” and “Although there are disagreements, couples are trying to support each other in providing care and balancing their other responsibilities.” Memos were continually compared to incoming data throughout data analysis and writing.

Theoretical sensitivity. Theoretical sensitivity is defined as having knowledge and awareness pertinent to the substantive area, without having a predetermined hypothesis or prediction about what will emerge from the data (Glaser, 1978). Two of the researchers, as clinicians, work directly with clients experiencing eating disorders and their families, enabling them to acquire insight into caring for persons with eating disorders. The third researcher also had much experience in couples' relationships, adolescent health, gender roles, and working with vulnerable populations, including persons with chronic illnesses. To prevent the forcing of data into predetermined conceptualizations (Glaser & Strauss, 1967; Glaser, 1978), the primary author memoed about her previous beliefs and experiences as a clinician prior to analyzing the data to

help ensure that she remained open to the data in order to allow the theory to emerge (Appendix B).

Rigour

Criteria for rigour in grounded theory studies are “grab,” “fit,” “work,” “relevance,” and “modifiability” (Glaser, 1978). The finding of couples becoming change agents is instantly appealing because it is strengths-based and involves positive movement. The participants who replied to the midterm summary agreed that the theory fit their situation and worked in representing their experience. For example, one participant replied “After reading your findings I was reminded of how alone I felt in dealing with my daughter’s eating disorder, with respect to my husband. I do think you acknowledged this.” The findings demonstrated relevance to the area of study in providing further insight into a minimally studied area in eating disorders research. Modifiability is possible as new data are added to the emerging conceptualization (Glaser, 1978). The substantive theory of *couples becoming change agents* was also independently reviewed by Dr. Herbert Orlik, a psychiatrist who has expertise dealing with persons who have eating disorders, furthering the rigour of this study. The grab, fit, work, relevance, and modifiability will continue to be assessed as the theory is published and disseminated.

Findings

The transformative process of becoming change agents for couples supporting daughters living with eating disorders involves movement along intertwined pathways (reflecting, coping, and strengthening resilience) that occurs over three stages of surviving the initial period, juggling responsibilities, and expanding supportive roles

(Figure 1). Couples reflect by comparing their perceptions and appraising potential options from their jointly informed decision making. Coping involves using emotion-based (e.g. comforting each other) and cognitive-based strategies (e.g., problem solving as a couple and information seeking). Resilience (e.g., ability to grow amidst adversity) is strengthened by reflecting on and coping with their experiences. Having a partner with whom to discuss information, make decisions, and share required tasks assists couples in becoming change agents within their families and communities.

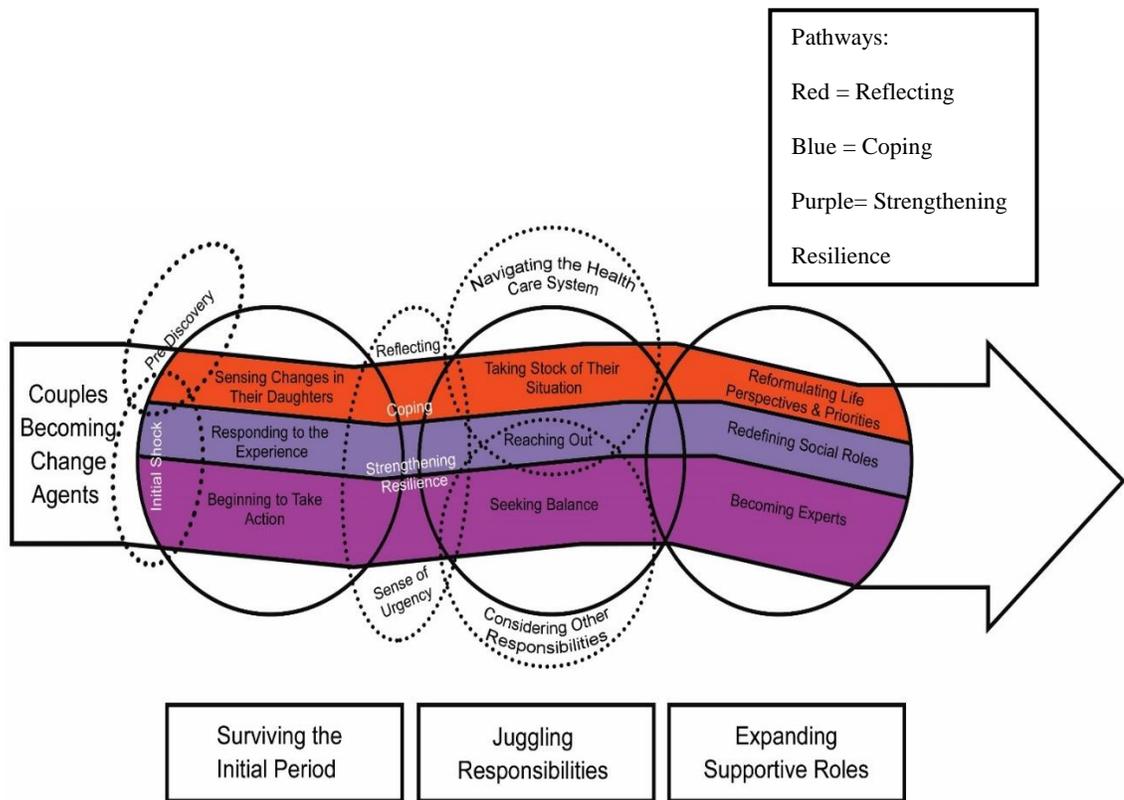


Figure 1: Couples’ Process of Becoming Change Agents in Caring for Daughters Living with Eating Disorders

The model (Figure 1) depicts the pathway of reflecting as initially recognizing changes in their daughters, taking stock of their changing situation, and reformulating

life perspectives and priorities. The pathway of coping shows couples responding to the threat to their daughters' health during the initial shock. They cope by reaching out to others for social support while juggling responsibilities, and later by redefining their social roles as individuals, couples, and community members. The pathway of strengthening resilience begins with the triggering of their need to act and subsequently balancing responsibilities of supporting their daughters amidst multiple competing demands; strengthening resilience propels couples in becoming experts.

Becoming Change Agents. Change agents are persons who have experience, commitment to a cause, and drive to promote change through providing guidance and leadership to others (Bruce & Parker, 2012). In our study, couples become change agents through moving along the pathways of reflecting, coping, and strengthening resilience while developing themselves as resources to foster change with their ill daughters. The process of becoming change agents begins during the initial period of discovering their daughters' illness, as couples realize they must support their daughter to improve her health. To support changes in their daughters' health status and ensure their daughters receive professional care, couples juggle their responsibilities such as financial and family commitments. Eventually, couples become experts, expanding their supportive roles through formally or informally sharing their experiences to raise awareness and public engagement about community needs for improved eating disorder resources and services.

Reflecting. An in-depth view of events, reflection involves considering life situations and anticipated future responses (Wain, 2017). The pathway of reflecting enables people to deeply consider what their concerns are, how to get help, and what

strategies are effective (Watts, 2003). In this study, couples appraise what priorities they have as they move through their process of becoming change agents. Reflections are intertwined with coping and help couples strengthen their resilience to become change agents for themselves, and their daughters, families, and communities.

Coping. Cognitive (Folkman & Moskowitz, 2004; van der Sanden, Pryor, Stutterheim, Kok, & Bos, 2016), emotional (van der Sanden et al., 2016), and behavioural (Folkman & Moskowitz, 2004; van der Sanden et al., 2016) strategies help both individuals and couples cope with increased stressors (Donato et al., 2014). In this study, the pathway of coping is the interplay between the individual and collective cognitive and emotional strategies couples use to move through the difficulties experienced during their process of becoming change agents. Individual strategies include personal health practices such as physical activity, resting, and engaging in religious or spiritual activities. Within couples, partners cope by communicating with each other about their thoughts and feelings (Bodenmann, 1995; Falconier, Jackson, Hilpert, & Bodenmann, 2015; Traa et al., 2015), gathering information (Bodenmann, 1995), and problem solving (Song et al., 2012; Traa et al., 2015). Coping enables couples to develop and draw on personal assets as well as the resources of their partners, families, and communities.

Strengthening Resilience. Resilience is a concept that is not consistently defined across the literature (Limardi, Stievano, Rocco, Vellone, & Alvaro, 2015; Peters, Jackson, & Rudge, 2011; Reivich, Seligman, & McBride, 2011; Walsh, 2016; Williams, 2016). There is dispute about whether resilience is an inherited characteristic or something that develops due to dealing with difficult stressors (Ahern et al., 2006;

Walsh, 2016; Williams, 2016). For this paper, resilience is defined as persons' ability to effectively cope, adapt to adverse situations, and grow or learn from them (Ong et al., 2009; Reivich et al., 2011; van Abbema, Bielderma, De Greef, Hobbelen, Krijnen, & van der Schans, 2015; Walsh 2003; Walsh 2016). We did not aim to dispute the origins of couples' resilience, but rather to focus on their process of strengthening resilience as they become change agents in caring for daughters living with eating disorders.

Drawing on resilience developed during previous life contexts, couples adjust their lives to meet their ill daughters' needs. The dynamic pathway of strengthening resilience is based on couples' reflecting on and coping with their experiences (Walsh, 2016) as they adapt their couple and family dynamics in response to their ill daughters' changing health status. The reflective component enables couples to learn throughout the process, and subsequently grow through reconsidering their priorities and values as couples and as individuals. Coping enables capacity to tolerate and hold tensions arising in the context of supporting an ill child. Resilience within relationships is largely impacted by resilience factors such as coping through giving and receiving support (Bishop & Greeff, 2015; Deist & Greeff, 2017; Walsh, 2016). In the theory of becoming change agents, couples also strengthen their resilience by seeking help, managing emotions, and following through on decided plans.

Surviving the Initial Period of Interpreting their Daughters' Symptoms as Eating Disorders

During the initial period of interpreting their daughters' eating disorders, couples move through three sub-stages: pre-discovery, initial shock of the illness, and sense of urgency to get help. In the pre-discovery sub-stage, they begin to notice

differences in their daughter, but may not recognize the array of symptoms as an eating disorder. Then, the normal functioning within the couple and family relationships are affected by the shock when they begin to understand the source of these symptoms as being the eating disorder and feel the urgency of their daughter's illness.

Pre-discovery. During the pre-discovery sub-stage, couples go about their usual patterns of decision making for work, leisure, child rearing, and household routines. Of the four married couples, three were comprised of both spouses working outside the home and sharing the child rearing and other household routines. One married couple had the father working outside the home and the mother staying in the home; with the mother performing most of the child rearing and household routines while the father contributed the household income. Both members of the divorced couple worked outside the home, interacted frequently with each other, and responded to the concerns of their child who lived with both her mother and father during her illness. Couples' process of becoming change agents begins as they recognize and discuss emerging changes in their daughters, such as fluctuations in weight, mood, and level of activity. Initially, couples may have difficulty identifying the symptoms as an eating disorder (Williams, 2011), as many daughters deliberately hide their illness by engaging in secretive behaviours, such as dressing in baggy clothing and concealing purging behaviours.

As couples discern a pattern of symptoms and behaviours, they further discuss their individual perceptions. Differences of opinion about the significance of their daughter's changes and disagreement within couples (e.g., about the meaning of symptoms) may demonstrate a healthy relationship, in which each partner is able to

contribute his/her own ideas; the differences expressed often lead to creating change (Dorrance Hall, 2017). Some couples or individual partners initially attribute these signs to be healthy developmental changes (Thomson et al., 2014), such as moving into adolescence, participating actively in sports, dealing with peer pressure, and conforming to societal beauty ideals. Others sense the changes in their daughters as a threat, leading to further discussion about the meaning of the symptoms. One participant reflected on this process of sensing changes, noting, “It’s pretty overwhelming and discouraging before you know what’s taking place.” Often, couples communicate with each other about their daughter’s changing behaviours and appearance sharing their feelings about their experiences and emotional responses, as they try to cope with the emerging changes in their daughters (Falconier, Jackson, Hilpert, & Bodenmann, 2015; Hinneken, Lemmens, Vanhee, & Verhofstad, 2016; Ledermann, Bodenmann, Rudaz, & Bradbury, 2010).

Couples commonly use their baseline couples’ coping strategies such as gathering further information (Bodenmann, 1995; Margola, Donato, Accordini, Emery, & Snyder, 2017) and communicating with each other (Bodenmann, 1995; Falconier, Jackson, Hilpert, & Bodenmann, 2015; Traa et al., 2015) about their observations and interpretations during pre-discovery. Individual coping strategies, such as physical activity, coaching sports, engaging in religious or spiritual activities, and/or studying are also employed. Couples’ actions during the pre-discovery are influenced by previous individual resilience factors such as finishing school, building work experience, overcoming moving frequently as a child, and managing family illness or death. For example, when one partner had previously experienced illness, the family was able to

transfer their previous knowledge of the health care system to support their ill daughter. Commonly, seeking more information about their daughters' evolving health ultimately leads couples to discover their daughters' eating disorder.

Initial shock when discovering the eating disorder. Becoming change agents is furthered as couples respond to their daughters' emerging symptoms (Figure 1). One partner noted, "It is like working something with a fine-tooth comb. You really get into the details of it and try to understand it [the eating disorder symptoms]." This need for specific information about eating disorders leads to a desperate search for information through ongoing conversations and observations. Some discover their daughters' eating disorder by their daughters' disclosing the illness or couples interpreting the stark deterioration in their daughters' physical health. One partner noted:

We were getting ready to go away on vacation and she just bought herself a new bathing suit and wanted me to look at it. When I walked in the bedroom I couldn't believe it was my daughter. She [had] bones protruding everywhere. That's when I realized how serious it was.

Some daughters choose to let out their eating disorder by sharing the stark change in their appearance with their parents. Many couples also notice psychological changes in their daughters. For example, one partner recalled, "Our daughter's personality had changed; she was listless, withdrawn, and totally consumed with finding ways to hide food. She was jogging and exercising compulsively; she was eating with small spoons, bowls, and plates." These physical and psychological changes shock couples, especially as they recognize these changes as evidence of an eating disorder. Discovering a child's eating disorder is stressful for parents (Whitney, Haigh, Weinman, and Treasure, 2007),

as shown by one partner noting, “There was some panic involved because eating disorders are a serious disease.”

In responding to the eating disorders discovery, couples may cope by using emotion-based strategies such as supporting each other and openly communicating about their sense of blame and inadequacy. Reflecting on past experiences, where members of a couple worked together to overcome difficult situations together brings them hope that they will have similar support in the current situation (Nurullah, 2012; Ryan, Wan, & Smith, 2014).

When individuals or both members of a couple cope by denying that the symptoms are an eating disorder, blaming themselves and/or each other, or arguing about their perspectives, they may perceive that the eating disorder strains the marital relationship (Whitney et al., 2005) or as one participant remembered, “it pulls you apart as a couple.” Couples often cope by referring to the eating disorder as a separate entity, which may lessen blame towards the ill child (Honey & Halse, 2006) but does not prevent partners from blaming themselves for their child’s illness (Whitney et al., 2005). Denial or minimizing the effects of eating disorders is common when one or both partners hope it is “a phase” that their daughters will overcome on their own.

Partners may blame each other, with husbands being more likely to blame their wives. One husband noted, “I blamed her [his wife] when we didn’t know what the eating disorder was all about because my daughter idolized models and my wife always bought her the nicest clothes and [told her] to look her best.” His wife perceived this blame, stating, “I think at first my husband blamed me too; [he would say] you gave her everything.” During the shock of discovering their daughters’ eating disorders, couples

often blame each other as they try to make meaning of their daughters' illness. This blame is commonly based on assumptions that eating disorders are caused by one factor such as perceived beauty ideals, instead of an array of interplaying factors (Culbert, Racine, & Klump, 2015; Petrie, Greenleaf, Reel, & Carter, 2009; Tall, 2009).

Couples whose relationships are strained prior to their daughter's eating disorders may be more likely to blame each other. This is particularly true if partners hold different values (such as the importance of aesthetics). It is even more difficult when the blame partners project on each other serves to question their partners' values and parenting roles. A consequence of this negative coping is a breakdown in communication that can occur when partners feel misunderstood and lonely within their couple relationship (McNeill et al., 2014). The quality of their relationship is further diminished when couples do not stick to the current issue but raise previous unresolved arguments (McNeill et al., 2014).

Whether or not members of a couple blame his/her partner for their daughters' illness, most blame themselves (Whitney et al., 2005). In this study, all participants blamed themselves for their daughters' eating disorder. One partner stated, "I blame myself for an awful lot of stuff, like if I was a better parent... I felt that if I was there more, if I had paid more attention, maybe some of this wouldn't have happened." As couples try to understand the illness development, they often initially blame themselves as they seek answers. In many cases guilt emerges from self-blame. Guilt is defined as feeling responsible for the impact of one's actions on others and is often associated with feelings of tension, regret, and remorse (Duncan & Cacciatore, 2015). One participant expressed, "From day one, it doesn't matter if your child is in kindergarten and they're

acting up, you figure what am I doing wrong with this child? You know, so [I] definitely felt guilt. Big time.” Parents often feel guilt related to their child’s mental health and question how their personal characteristics, parenting behaviours, and relationship issues influenced mental illness development (Cohen-Filipic & Bentley, 2015). Feelings of inadequacy and helplessness compound the pain of this guilt. One partner reflected feeling inadequate as a parent, stating “We didn’t know anything about eating disorders and the long-term problems.” This statement is an example of the unspoken assumption that parents ought to know about potential risks to their children, so they can protect them from harm.

In many cases, the guilt that emerges from self-blame leads couples to isolate themselves from family and friends because they are consumed by overwhelming feelings of inadequacy and perceived responsibility for causing their daughter’s illness. One participant noted, “It’s a feeling of loneliness because you’re in a life-threatening situation with very limited resources. It’s a disorder relatively unknown to our friends and family.” Anticipating blame from others, couples may recluse themselves from social situations to protect themselves and their child from further difficult feelings of guilt, shame, and perceived stigma from others.

Couples are frequently unable to draw on many of their previous coping strategies during this initial shock due to feeling emotionally immobilized (Purcell, 2016). In this study, guilt related to their daughter’s illness immobilizes couples. One of the main advantages of the couples’ relationship during this shock is the ability of partners to share the intense emotional responses and receive empathy from each other (Levesque, Lafontaine, Caron, Flesch, & Bjornson, 2014). Given that couples feel

personally responsible for their daughters' illness, they gain a sense of urgency to learn more and change their behaviours in efforts to improve their daughters' health.

Sense of urgency. As couples realize the seriousness of the situation, they feel a sense of urgency to get help (Figure 1). Urgency is a catalyst in couples' process of becoming change agents and is influenced by their previous life experiences, prior knowledge of eating disorders, and fear that their daughter may die. A mother explained, "It's the same thing as if the child had cancer or diabetes. It's a life-threatening disease." The health consequences for their daughters are so severe that, during this sub-stage of urgency to get help, couples compare the eating disorder to other serious health concerns.

Decisions about accessing help are influenced by the couple's decision-making patterns, whether this involves one partner taking responsibility to make the decisions or both deciding together. For example, one father noted, "The action to get help was driven by my wife because she basically took it under her responsibility to do that and so [I] supported and went along with it." It was more common for mothers to take on decision-making responsibility, which may indicate traditional gender roles in the couple. Other couples engage in a mutual process where they collaborated on the plan of action. How quickly couples access health care services is influenced by couples' interpretations of their daughters' symptoms (Thomson et al., 2014). Perceived accessibility and availability of resources, differences in parenting styles, and couples' previous experiences in the healthcare system further influence the timing of accessing care. During the sense of urgency, couples with younger daughters find it easier to seek help because they can insist their daughters be seen by health professionals. On the

other hand, a couple who had an older daughter urgently wanted to take her to the doctor but were constrained by her age and level of independence.

During this sub-stage, couples tend to use more cognitive-based coping than emotion-based coping. Together, they strategize approaches to get help, and urgently seek more information about eating disorders. Cognitive-based coping helps them make a plan responsive to their daughter's changing health status. Emotion-based coping (e.g., engaging in religious or spiritual activities) supplements the cognitive-based coping strategies. One participant highlighted the importance of her spirituality, noting, "You talk to God, ask for help from a higher power and that helps you deal with things better. I prayed a lot about it." Having a relationship with God (or another spiritual being) may give partners hope about the future and help them make meaning of their child's illness (Grossoehme et al., 2010; Purcell et al., 2015).

In summary, the stage of surviving the initial period of interpreting their daughters' symptoms as eating disorders entails becoming change agents through sensing changes in their daughters, interpreting the symptoms as an eating disorder, and responding to the daughters by beginning to seek professional care. The pathways of reflecting and coping help couples recognize the need for change, which strengthens their resilience as they begin to build resources that address the threat to their daughters' health.

Juggling Responsibilities

The stage of juggling responsibilities is centered on couples supporting change in their daughters' health status while balancing their other commitments. Couples take stock of their situation by considering limits within their couple and family units and the

health care system. They support each other and reach out for additional support from others in an attempt to seek balance in their lives. As couples cope with the variations of others' responses to their situation, they actively reflect on their relationship and responsibilities associated with their daughters' care. Their resilience is strengthened through an ongoing cycle of reflecting, making changes, and evaluating the effects of these changes on their daughters' health.

Navigating the health care system. The sub-stage of navigating the health care system is characterized by intertwined strategies of reaching out for support from others (coping) and taking stock of their changing situation (reflecting). A consequence of reaching out for professional support is developing increased knowledge and skills (Girz et al., 2013). Taking stock enables modifications to be made to the approach to the daughters' care based on couples' knowledge and resources. Resilience is strengthened through iterative processes of making changes and reflecting on the impact of these changes on the daughters. As couples strengthen their resilience through navigating the health care system, they further develop their process of becoming change agents.

Having health professionals involved in their daughters' care is a relief for couples who "don't have to be the bad guys anymore." As couples take stock of their situation, they continue to experience guilt related to their daughters' illness, which lessens as they receive professional support. This support helps couples better understand ways to manage the eating disorder symptoms and validates the positive aspects of their parenting roles. Given this, one participant noted "All couples would need counselling." Often, couples received support through public or private counsellors. Private counselling may impact the family's financial resources

(McCormack & McCann, 2015; Patel et al., 2014; Svensson et al., 2013). In this study, couples often perceived that private counsellors do not have a broad knowledge about eating disorders. As health professionals support couples and their daughters, couples can focus on being “supportive and a family.” In the literature, parents expressed that they missed having quality family time such as family meals (Fox et al., 2017; McCormack & McCann, 2015; Patel et al., 2014; Svensson et al., 2013; Treasure, Cardi, & Kan, 2012) and vacations (Whitney et al., 2005) during the acuity of their daughter’s illness.

In addition to professional support, couples who are actively involved in community support groups benefit from sharing their experiences (Lobera, Garrido, Fernandez, & Bautista, 2010; Pasold, Boateng, & Portilla, 2010; Svensson et al., 2013; Whitney et al., 2012). In the current study, one participant reflected:

It felt good to hear other people’s stories and to know that you weren’t the only one. To hear what other mothers had to say, and you know, other fathers. And to know that you weren’t the only one having these feelings.

Families who compared their stories with other families learned from each other and experienced decreased guilt and isolation (Lobera et al., 2010; Pasold et al., 2010; Svensson et al., 2013; Whitney et al., 2012).

Although the validation and support from reaching out reduces feelings of isolation, couples may still encounter dissonance between their expectations of the health care system and the reality they face. One participant was horrified in trying to get help for her daughter, noting, “We went to the emergency [room] one day and the

doctor said, ‘Well, what do you want me to do?’, and I said, ‘I’m not sure what, but I want you to do something.’” A perceived lack of resources reduces couples’ confidence in the health care system and compounds couples’ fears about their daughters’ declining health. Couples continue to take stock of and evaluate health care system resources (Figure 1). They perceive a lack of local specialized practitioners and experience long wait times to see available practitioners. To illustrate, one couple disclosed fear for their daughter’s life waiting three months to see a pediatrician, while “all that time we kept seeing her lose weight.” At times, feeling worried or controlled by the illness increased stress and arguments within the family (Whitney et al., 2005).

Couples experience power imbalances between themselves as couples and the health care system. They perceive not being a valued member of the team when they are excluded from treatment decisions. “We didn’t really agree on everything. We [the couple] formed part of the team at the hospital; well, not all the time, sometimes we were excluded.” Couples also reported discussing their concerns with each other about their daughters’ care, such as negative interactions with health care professionals (Silber, Lyster-Mensch, & DuVal, 2011). In the case when the daughters were older, couples were unable to access any information about the daughters’ experience from professionals, perhaps because of alleged privacy and confidentiality issues.

As couples act to help their daughters and encounter these power imbalances, they reflect on their own roles as parents. For some couples, a consequence of these power imbalances is increased guilt about their daughters’ eating disorder. One partner noted, “The first three weeks [of her hospitalization] we couldn’t see her ... I can’t believe you have to isolate a child from her parents, unless we would have been the ones guilty of

something.” In other instances, wherejn couples were unable to see their child, they often internalized guilt and perceived stigma from health care professionals (Whitney et al., 2007). Couples’ guilt is further intensified when they receive direct blame from health professionals.

From the time he [psychologist] came in the door he seemed to set his eyes on me, the mother. He started asking me questions. I felt like I was being attacked by him. And I felt like he was putting the blame for our daughter’s eating disorder on me. I just started crying. It felt like he was interrogating me. ‘Now why did you do this?’ ‘What did you do?’ And no questions were going to my ex-husband at all. You know, the father. It was all at me. And so of course I came away from that, I mean you carry guilt from day one as a parent... and I came away from that thinking it was all my fault. You know here’s a professional, a psychologist, and it really felt like it was my fault.

In the context of professional-directed blame and mistrust of the health care system, couples reflect on their role in contributing to the development of their daughters’ eating disorder. Couples engage in emotion-based coping strategies such as physically hugging each other and communicating their feelings. As well, they cope using cognitive strategies such as sharing knowledge, problem-solving, and decision making, while considering private or out of province resources as an alternative to local health care options.

Considering other responsibilities. While navigating the health care system to access help for their daughters and themselves, couples concurrently manage multiple demands such as addressing the needs of their other children, family members, friends,

work, education, and household duties. Summarized by one participant, “You are trying to carry on your regular household [tasks and events] [and] mak[e] sure your child is getting the intervention they need. There is a lot involved, none of it easy.” In considering their family’s needs, couples continually adjust their resources of time, energy, and money. Often couples had expressed feeling their own mental and physical health become compromised when trying to fulfill their competing demands (Whitney et al., 2005; Perkins et al., 2004). Couples’ resilience is strengthened as they continue to take stock of their situation, discuss and define their roles within the couple relationship, and reach out for support.

A condition that influences couples’ ability to manage their other responsibilities is reflecting on each other’s strengths and preferences. For example, some of this study’s couples divide work and childcare responsibilities equally; in other couples, one partner meets financial needs while the other partner primarily provides care. Individual partners who do most of the caregiving find it “stressful and frustrating.” This additional stress may affect the couple relationship and their ability to meet their own needs (Nakonezny & Denton, 2008; Paat, 2013). Couples in this study make sacrifices related to their own education, physical activity, and social time with others to attend to their daughters’ changing health status.

Caring for an ill daughter is sometimes described as a “24/7 job” which makes it difficult for some partners to work while navigating the health care system. Seeking balance (Figure 1) involves adjusting work schedules. Reducing work hours or re-arranging schedules are two cognitive coping strategies couples employ to balance the needs of their daughters, themselves as a couple, and their families.

Many tasks within the couple relationship need consideration during their child's illness including the division of housework, labour outside the home, childcare duties, and expressions of intimacy (Nakonezny & Denton, 2008; Paat, 2013; Sutphin, 2010). Reaching out to family and friends for emotional support and assistance with family tasks helps couples to find balance in juggling their responsibilities. Emotional support is highly valued by the couple, with one partner adding, "I talked to friends. I have a group of guys [I] get together with. I am really blessed with a good network of male friends." Seeking emotional support from friends and family has been identified as enabling open communication of thoughts and feelings outside of the couple relationship (Svensson, 2013). Family and friends also help with family tasks of childcare, meal preparation, and transportation to appointments.

Those couples who do not reach out anticipate negative reactions, including limited knowledge about eating disorders, and insensitivity on the part of family and friends. Disclosing their daughter's illness to family and friends may induce further blame from others. Indeed, when one partner told her friend about her daughter's eating disorder, her friend asked, "When you were young what kind of problems did you have?" And I said, 'I did not have any problems really... I am low enough right now, do not start blaming me.'" As in this example, mothers encounter blame from friends and the health care system more often than fathers.

To summarize, the stage of juggling responsibilities, comprised of sub-stages of navigating the health care system and maintaining work and other family responsibilities. It is operationalized by a cycle of taking stock through reflection and reaching out for support. In this way, couples' resilience strengthens by trying out

different strategies, reflecting upon them, and learning from them. Altogether, the processes of reaching out, taking stock, and seeking balance help couples cope with stress and facilitate change as change agents for their daughters and families.

Expanding Supportive Roles

The stage of expanding supportive roles is centered on couples reformulating life perspectives and priorities, redefining social roles, and becoming experts in eating disorders support (Figure 1). Redefining social roles and reformulating life perspectives and priorities creates changes within family relationships. Through repeated monitoring, developing knowledge, and practicing skills to help their daughters continue to recover, couples develop confidence and identify themselves as experts. Their expertise fosters change within their families, and for some, within their communities.

Reformulating life perspectives and priorities. As couples reflect upon their experiences in caring for their daughters, they shift their life perspectives and priorities. They often “let go of the small things” as they have overcome a serious health threat in their family. Couples further demonstrated valuing the primacy of their relationship by spending time together and taking care of each other through expressing love (Cuenca-Montesino et al., 2015; Graham, 2011; Harris et al., 2016) and commitment (Frost & Gola, 2015). When reflecting on their experiences, one partner noted, “We were not a couple. We had to learn to do it just the two of us. We take care of ourselves as a couple.” Couples often create a more secure attachment within their relationship with each other as the threat of their daughters’ illness lessens. For example, “Wife and I, it’s made our relationship even stronger.” According to one partner of the divorced couple, his relationships with his previous and current wives remained strong; however, the

relationship with his previous wife did not deepen further following their daughter's recovery. Within many families, couples prioritize their shared values (Frost & Gola, 2015; Harris et al., 2016). Values of health and happiness are operationalized by spending time as a family instead of doing previously important tasks such as household chores.

Redefining social roles within families. “We [family] were always so close, it has made us even closer.” Many couples recognize the positive aspects of their process of becoming change agents, largely because of the connection or reconnection of relationships within their families. Couples redefine their social roles within their families based on their changing perspectives and priorities (Figure 1). They continue to use coping skills of communicating and providing social support as they redefine their relationships with each other and their family members. Many partners feel they are no longer “the enemy [to their daughters]” and that they have a better relationship after recovery than prior to the illness. For example, one participant noted a change in his relationship with his daughter, stating, “I am not sure we would have come this far in our relationship if it wasn't for having to deal with this [eating disorder].” Often, couples become closer to their daughters as the eating disorder behaviours reduce. Siblings of a girl with an eating disorder also spend more time together and reconnect with her during this stage.

Becoming experts for their daughters. Changes in daughters' health status are a consequence of couples' support. As daughters recover, couples promote their daughters' independence based on age and developmental level (Lock & Le Grange, 2013). Couples become experts by reflecting together on their experiences caring for

their ill daughters. Based on their daughters' levels of recovery they guide their daughters' return to developmentally appropriate tasks such as socializing with peers, dating, (re)engaging in leisure activities, moving out of the family home, and (re)engaging in their education (such as returning to university). Couples may continue supporting their daughters' food intake and weight restoration/maintenance to manage relapses (Lock & Le Grange, 2013).

Becoming experts within families. Change is created in family relationships through reflecting on the shifting social roles and life priorities. As they see their daughters' health status improving, couples make changes within their relationships with each other and within their family unit. Couples attribute their developing expertise to their confidence in using the knowledge and skills they have built while managing their daughters' illness (Girz et al., 2013). In this study, participants expressed feeling calmer, more understanding and empathetic, and less judgmental with themselves, their family members, and others.

Becoming community experts. All couples become experts with their daughters and families, and some expand their expertise in becoming community change agents. Couples expand their roles as community experts (change agents) only once they are sure their daughters are safe from the threat of the eating disorder. They have gained confidence (Girz et al., 2013) in how to support their daughters if relapse occurs. The study participants shared "knowledge, experience, and understanding to help someone [else like other daughters and families]." Couples hold formal and informal leadership roles within support and provincial advisory groups; sharing information and resources with members of these groups. In this study, couples promoted public

awareness through activities such as creating a film about eating disorders, sharing their experiences on a live radio broadcast, and participating in public marches. As community advocates, they create and seek out public platforms to lobby that “The government should really invest in [reducing eating disorders].” Goals of lobbying include increasing community and government engagement about eating disorders care and services.

Summary of the Findings

Couples’ process of becoming change agents evolves through stages of surviving the initial period, juggling responsibilities, and expanding their supportive roles. This process is not strictly linear because couples are circling back to juggling responsibilities based on their daughters’ health status. The process of becoming change agents comprises reflecting and coping, which together, strengthen their resilience. Their movement along the pathways depends on their daughters’ changing health needs. This process challenges and positively influences couples’ attachments to one other as they work together to create changes in their personal lives and communities.

Discussion and Implications

This substantive theory addresses a minimally studied topic and is a unique contribution to the literature as it highlights the dynamic process couples go through when supporting their daughters in recovering from their eating disorders. Couples’ process of becoming change agents conveys their complex individual, collective, and relational changes as they cope with the emotional, cognitive, social, and spiritual aspects of having an ill daughter.

From this analysis, we have learned that couples' resilience is influenced by their communication with each other and their ability to work together to meet their competing demands. Our findings support others' results that couples' resilience also includes a sense of closeness between partners, where open communication (Jamison, Coleman, Ganong, & Feistman, 2014), love (Cuenca-Montesino et al., 2015; Graham, 2011), mutual respect, trust, and satisfaction are present and help preserve or strengthen their relationships and well-being when dealing with difficult circumstances (Martin et al., 2014; Martin et al., 2016; Sanford, Backer-Fulghum, & Carson, 2016). Reflecting (together and individually) aids couples in recognizing the eating disorder symptoms and considering the effectiveness of their coping and caregiving strategies. Couples in our study used mutual coping strategies such as joint problem-solving, information gathering, and communicating openly, which are similarly described by Bodenmann (1995), Song et al., (2012), and Traa, De Vries, Bodenmann, and Den Oudsten (2015).

Our findings identify the preconditions to becoming change agents as dependability in the couple relationship, ability to express themselves, and working together to support their daughters in improving their health. Couples' social exchanges of sharing family responsibilities (Blau, 2009) are vital to their process of becoming change agents, particularly during the stage of juggling responsibilities because they have multiple competing demands to strategize about and complete. Couples divide required responsibilities in numerous ways to designate the time and efforts to access professional help for their daughters and to manage other work and family responsibilities (Nakonezny & Denton, 2008; Paat, 2013; Sutphin, 2010).

Other researchers began studying the role of parents as change agents in supplementing health services, as early as the 1970s (Atkeson & Forehand, 1978; Reisinger, Ora, & Frangia, 1976). Although the term “change agents” is not necessarily used in the literature, health professionals continue to see the social and economic value in involving parents in creating change with their children (Ball, Mushquash, Keaschuk, Ambler, & Newton, 2017; Forsberg, LoTempio, Bryson, Fitzpatrick, Le Grange, & Lock, 2013; Lanovaz, Rapp, Maciw, Dorion, & Prgent-Pelletier, 2016). Our study furthers this viewpoint, namely that clinicians need to collaborate with couples, understanding the dynamic power of partners working together for their child’s health.

Implications for practice. Our model (Figure 1), will give health professionals a greater understanding of couples’ support needs as they become change agents. In our sample, couples perceived being judged by health professionals and excluded from treatment. When health professionals engage in open, supportive communication with couples, power imbalances and negative interactions will be less likely to occur. Collaborating in decision making (Doody, Butler, Lyons, & Newman, 2017; Tambuyzer, Pieters, & Van Audenhove, 2011), providing accurate information (Eldh, Ehnfors, & Ekman, 2005), and considering client (daughters and couples) preferences (Doody et al., 2017; Montori, Brito, & Murad, 2013) are specific strategies health professionals can use to decrease power imbalances through increasing collaboration in care. This collaboration will further enable health professionals to advocate for couples’ needs.

Couples will gain confidence in their change agent roles when health professionals provide emotional support and education, facilitate skill-building, and help

couples find required resources (Ciao, Accurso, Fitzsimmons-Craft, Lock, & Le Grange, 2015; Girz et al., 2013; Halvorsen & Heyerdahl, 2007). Commonly, the focus of therapy is on daughters without caregivers' needs being met (Fox et al., 2017). In not meeting couples' needs as parents, the child's needs are not fully addressed as parents often influence decisions at home about the selection of food, eating patterns, and meal structure (Golan & Crow, 2004; Marcos et al., 2013; Rodgers, Faure, & Chabrol, 2009). An assessment of couples' existing and required support within their couple relationship will enhance health professionals' understanding of required support. An ongoing evaluation is required, as couples' needs change throughout their process (Fox et al., 2017). If invited, health professionals can also take part in community groups and events to lend support and provide scientific information that can help correct myths about eating issues and treatment.

Implications for education and health policy. Couples advocated for further education about eating disorders in the education system and with the general public. As well, they advocated for local practitioners to have more specialized eating disorders knowledge. Since these interviews took place, the Mental Health Commission of Canada put forward strategies to improve mental health in Canada by increasing promotion and prevention programming, improving access to services, embracing diversity, and calling Canadian citizens to take action (2012). More recently, however, an article written for CBC News highlighted the barriers of time, travel, and financial constraints that New Brunswick residents with eating disorders face when trying to receive treatment at the closest treatment facilities which were in Nova Scotia (Yard, 2016). So, although the Metal Health Commission of Canada recommended strategies

to improve mental health care in relation to the situation of families with a family member with an eating disorder, these requirements have not been addressed.

We recommend that government and policy-makers integrate more couple-based information and eating disorder information into health-related college and university programs and provide guidelines and information to already practicing health professionals. Mahr et al. (2015) similarly suggested simulated learning, web-based learning, and increasing clinical hours as strategies to help future practitioners learn about eating disorder care. Teachers and others working with children and youth in the school system would also benefit from further education about eating disorders to promote earlier recognition and treatment (Yager & O’Dea, 2005). Community health nurses in schools could be a valuable resource for students, teachers, and parents to improve eating disorders detection, education, and care in the school environment (Funari, 2013; Tall, 2009).

Research implications. The theory of couples becoming change agents highlights the importance of additional research needing to be done about couples’ experiences and perspectives. Given that the sub-stages of pre-discovery and sense of urgency to get help were not saturated in our current study, further research about couples’ experiences before and after discovering their daughters’ eating disorders could further health professionals’ understanding of couples’ experiences. Early detection and education from primary health providers could help couples detect symptoms earlier and impact the care couples and their children receive.

Strengths and Limitations

Using secondary analysis of a sub-set of previously collected data was an efficient and respectful use of participants' contributions as it provided a theory and model that can increase knowledge and awareness about couples' experiences. However, the primary author did not do the interviews herself and the data set was limited to the transcriptions of the interviews. Given this, the primary author could not hear the emotional tone of the interviews, which would have enhanced her understanding of how the couples were affected by their daughters' eating disorders.

This study was conducted with a small homogenous sample, (i.e., all the couples comprised male and female partners who had daughters living with eating disorders, were mostly married, Caucasian, English-speaking, with a post-secondary education). Future research should include the perspectives of more diverse couple and child populations from different genders, sexual orientations, socio-economic statuses, cultural backgrounds, and geographic regions.

In closing, the substantive theory of *couples as change agents* illuminates the need for further advancements in research, practice, policy, and education about the roles of couples in providing care and supporting their children living with eating disorders. The power of spouses working together to manage children's health issues needs to be further researched to enhance health professionals' knowledge on how to better support couples.

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Chapter 3: General Discussions and Conclusions

Parents of persons experiencing eating disorders require additional support to improve validation, boundary-setting, and coping skills through psychoeducation (Hibbs, Rhind, Leppanen, & Treasure, 2015; Whitney, Currin, Murray, & Treasure, 2012) and skills-based training (Goodier et al., 2014; Whitney et al., 2012). These therapeutic techniques have been found to reduce *parents'* (as individuals) levels of distress and perceived burden (Goodier et al., 2014; Hibbs et al., 2015), increase insight into the illness (Whitney et al., 2012), and raise their caregiving self-efficacy (Goodier et al., 2014). Although nurses play a significant role in applying these therapeutic techniques and fostering family-centered eating disorders care (Carter, Webb, Findlay, Grant, & Van Blvderveen, 2012; Davey, Arcelus, Munir, 2013; Kong, 2005; Silber, Lyster-Mensh, & DuVal, 2011), there is little known about how nurses respond to *parents as couples*. Our model (Figure 1), can help guide nursing practice, education, and research as it informs nurses about the change agent process couples go through during different stages of responding to their child's eating disorder.

As the principle investigator in this study, I am a clinician who works with families of children with eating disorders using a strengths-based nursing approach, described by Gottlieb (2013). Strengths-based nursing involves considering the resources and strengths of persons, families, and communities in overcoming health challenges (Gottlieb, 2013). This approach is different than the traditional deficit-based health care model as it focuses on the positive aspects of relationships and resources through collaboration, health promotion, and person-centered care (Gottlieb, 2013). Currently, my sessions with families involve communicating about and building upon

families' strengths to restore weight, interrupt symptoms, and manage changing family dynamics. The substantive theory and model developed from my MN thesis research will improve my strengths-based practice as it sensitizes me to the abilities couples have when they overcome challenges they face in their personal lives and in navigating the health care system. During my therapy sessions, I now will further support couples in expressing their reflections about their experiences, resources, and actions as we collaborate in decision making about their children's care (Doody, Butler, Lyons, & Newman, 2017; Tambuyzer, Pieters, & Van Audenhove, 2011). This decision-making process will be supplemented by providing accurate evidence-based information (Eldh, Ehnfors, & Ekman, 2005) and considering couples' and children's preferences (Doody et al., 2017; Montori, Brito, & Murad, 2013). As part of my sessions I will take more time to consider the relationships between partners to learn more about their support needs and assess if they are interested in further therapy, such as couple's therapy.

In some care settings, direct eating disorders supervision for front-line staff is recommended to improve nursing care for those experiencing eating disorders (Lowther, 2005). Advocating, collaborating, reflecting, empathizing, being non-judgmental, and expressing kindness are all parts of strengths-based nursing (Gottlieb, 2013) that can enhance nursing care related to couples. I intend to continue to disseminate this substantive theory within the context of strengths-based nursing in my resource role where I mentor and supervise other nurses, nursing students, medical students, and medical residents. Including information about couples' process will allow nurses and allied staff to better assess and support couples as they navigate the health care system. This theory of *Couples Becoming Change Agents in Caring for Daughters Living with*

Eating Disorders will be disseminated and tested in practice by both inpatient and outpatient staff. Further advocating for couples' needs will ultimately impact the care of children experiencing eating disorders.

Formal presentations will continue to be done in the community for college and university students at local institutions, teachers at in-services and conferences, and the public at community events as requested. These presentations will include the *Couples Becoming Change Agents* model and information about the process couples go through when caring for daughters living with eating disorders. I will advocate for resources on a local level at work and with my involvement in non-government organizations such as the provincial eating disorders support network. I am also part of a provincial eating disorders professional network and I plan to bring this information to an upcoming network meeting to open further discussion among provincial eating disorders experts. On a larger scale, I would be interested in sharing my substantive theory nationally and internationally through eating disorders and health care conferences. This theory will also be submitted to *Qualitative Health Research (QHR)* to expand the current literature about this sparingly researched topic. *Qualitative Health Research* is a peer-reviewed international, interdisciplinary health care journal that considers complete, finished manuscripts that meet the requirement of Sage Publications Inc. for qualitative research, and the guidelines contained in the *Publication Manual of the American Psychological Association* (6th ed.). I am also considering contacting parenting magazines such as *Parents Canada* or *Today's Parent* to publish a short article about couples' experiences to create awareness and give resources to couples or parents who believe their child might have an eating disorder.

I believe it is important for nurses to conduct research into eating disorders. Nursing-led research provides a holistic lens about participants' perspectives, is critical to the advancement of the nursing profession, and provides a base for optimal evidence-informed nursing care (Blake, 2016; Tingen, Burnett, Murchison, & Zhu, 2009). The theory of couples becoming change agents might open the way to additional research being done with more diverse couples, given that our sample was homogenous. Ideally, understanding diverse couple relationships could help improve health professionals understanding of how to support many more couples. I plan to be involved in nursing-led qualitative eating disorders research about siblings, couples, and other family members to further nurses and other health professionals' understanding of the process that persons go through while caring for someone living with an eating disorder. Given my interest in couple relationships while caring for children with eating disorders, a larger study with more participants from various backgrounds may be done within my current workplace.

In summary, this research project has expanded my understanding of couples' caring for children living with eating disorders. I will use this theory in my clinical practice and teaching. This theory may also inform lay persons and other health professionals about the process couples experience.

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Appendix A: Eating Disorders Criteria DSM 5 – Diagnostic and Statistical Manual of Mental Disorders 5th Edition

DSM 5

The Diagnostic and Statistical Manual of Mental Disorders (DSM) is a diagnostic tool used to classify and diagnose mental health issues including eating disorders (APA, 2013). The DSM 5 classifies eating disorders differently than its predecessor (the DSM-IV) to attempt to decrease diagnoses of Eating Disorders Not Otherwise Specified in the DSM-IV and Other Specified Feeding or Eating Disorder in the DSM 5. Those with Other Specified Feeding or Eating Disorder do not meet full criteria for anorexia nervosa, bulimia nervosa, or binge eating disorder (Birgegard et al., 2011; Dooley-Hash, 2013; Fairburn & Cooper, 2011; Machado, Goncalves, & Hoek, 2012; National Eating Disorder Information Centre [NEDIC], 2014). The DSM 5 has a different diagnostic criterion for anorexia nervosa and bulimia nervosa, and recognizes binge eating disorder as a formal eating disorder (APA, 2013). The DSM 5 allows for more clinical judgement by changing previous cut off points (for frequency and duration) and to allow practitioners to use their discretion (Mannix, 2012).

Anorexia Nervosa

Anorexia nervosa is a serious mental illness with a relatively poor long-term prognosis (Rigaud, Tallonneau, Brindisi, & Verges, 2012). Persons with anorexia nervosa experience a disturbance in body image where they perceive themselves to be much larger than they are (APA, 2013). Often, persons with anorexia nervosa address this by limiting their diet, engaging in excessive physical activity, and/or using laxatives or other methods that assist in weight loss (APA, 2013; Jacobsen, 2014). Persons with

anorexia nervosa have an intense fear of gaining weight and think about food a lot; they may do activities such as weigh foods, weigh themselves multiple times a day, or play with food instead of eating it (APA, 2013; Department of Health and Human Resources USA, 2009).

Anorexia nervosa has two subtypes; (a) restricting type and (b) binge-eating/purge type (APA, 2013). The restricting subtype is classified as weight loss that happens primarily through excessive exercise, fasting, and restricting food intake within the past 3 months (APA, 2013). The binge-eating/purging subtype is classified as recurring episodes of bingeing and/or purging within the past 3 months, with a low BMI distinguishing it from bulimia nervosa (APA, 2013). The severity of anorexia nervosa is based on body mass index (BMI) which is the ratio of body weight in kilograms to the square of its height in meters (APA, 2013; Merriam-Webster, 2014). Seventeen kg/m^2 classifies mild anorexia nervosa and extreme anorexia nervosa is classified as a BMI of less than 15 kg/m^2 (APA, 2013).

Bulimia Nervosa

Bulimia nervosa is characterized by distinct episodes of binge eating and frequent compensatory behaviours such as purging, excessive exercise, laxative use, and/or the use of other medications to eliminate food from the body (APA, 2013). According to the DSM 5, bulimia nervosa is diagnosed based on the amount of compensatory behaviours per week (APA, 2013). In mild bulimia nervosa compensatory behaviours occur on an average of 1-3 episodes per week and in extreme bulimia nervosa they occur on average of 14 or more times per week (APA, 2013). Persons with bulimia nervosa characteristically self-evaluate based on weight, feel a lack of control when

binge eating an excessive amount of food in a short period of time, and may feel relieved after purging the ingested food (APA, 2011; APA, 2013).

Binge Eating Disorder

Binge eating disorder is characterized by frequent episodes of uncontrollable overeating that may lead to rapid weight gain (APA, 2011; APA, 2013). Persons with binge eating disorder tend to have higher levels of food cravings before and after eating and consume more food when compared to normal weight and obese controls (Ng & Davis, 2013). According to the DSM 5 (2013), the severity of binge eating disorder goes from mild (1-3 binge eating episodes per week) to extreme (14 or more binge eating episodes per week) over a three-month period. Persons with binge eating disorder do not use compensatory behaviours but often feel guilty about their eating habits (APA, 2013).

Other Specified Feeding or Eating Disorder

According to the DSM 5, if the criteria for anorexia nervosa, bulimia nervosa, or binge eating disorder are not fully met the eating disorder may be classified as other specified feeding or eating disorder (APA, 2013). This category of eating disorders includes the following sub-diagnoses: (a) atypical anorexia nervosa (meets AN criteria except weight is in normal range), (b) bulimia nervosa of low frequency and/or limited duration (binge eating and compensatory behaviours happen less than once a week and for less than a three month period), (c) binge eating disorder of low frequency and/or limited duration (binge eating does not meet criteria in three month period), (d) purging disorder (excessive compensatory actions after ingesting a small amount of food), (e) night eating disorder (eating after awakening from sleep) and (f) other specified feeding

or eating disorders (APA, 2013). These eating disorders vary in presentation of symptoms (APA, 2013; NEDIC, 2014).

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Appendix B: Letter to Self

May 25th, 2015

Dear Melissa,

Surprisingly, I do not have many preconceived notions about couples' perspectives in caring for daughters living with eating disorders. Much of my personal experience has been with single parents or with just mothers being involved in meetings and meal support.

I do believe that mothers are the primary caregivers to daughters living with eating disorders. I believe they may have closer relationships with their daughters than the fathers do. I believe both partners blame themselves throughout the process but deal with it differently.

I think perhaps couples fight during their daughters' eating disorder and it affects the whole family. I also believe people can come closer through adversity.

Melissa

Curriculum Vitae

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Conference Presentations:

MacDonald, H., & Hilchey, M. (2013). Returning to work after depression: Implications for women's health. UNB Nursing Research Day, Fredericton NB.

Hilchey, M., & Weaver, K, (2014). Parents' perspectives of having a child with an eating disorder. UNB Nursing Research Day, Fredericton, NB.

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