# THE SUPPORTIVE CARE LANDSCAPE FOR YOUNG WOMEN WITH BREAST CANCER: A BROAD OVERVIEW AND A FOCUSED INVESTIGATION OF THE COUPLELINKS INTERVENTION

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# Abstract

Objectives: This two-study dissertation broadly investigated supportive care interventions for young women with breast cancer (YWBCs). Study 1 aimed to overview the types of psychosocial programming for YWBCs in English-speaking regions developed in both academic/hospital and community domains. Study 2 examined an online, couple-based, YWBC intervention called Couplelinks. The purpose of this study was to identify mechanisms underlying change observed in couples with improved outcomes.

Methods: Study 1 consisted of a scoping review and environmental scan of supportive care resources. In addition to describing the models of care available, we compared and contrasted the different types of support developed in hospital versus community settings, and explored the differing praxis associated with each that underlies the development of YWBC care. Study 2 consisted of a task analysis, a psychotherapy process method, to differentiate between successful and unsuccessful participation in Couplelinks as defined by scores on relationship adjustment post-treatment as measured by the Revised Dyadic Adjustment Scale.

Results: The findings of Study 1 showed a high focus on education pertaining to age-related side effects of breast cancer treatment, as well as various types of content and methods of delivery for psychosocial support in both academic and community-based programs. A hybrid-type model of care was identified and deemed to be optimal because of its comprehensiveness and ability to integrate both domains. The findings of Study 2 revealed themes that were distinguishing of successful couples, such as high utilization, a sense of alignment, and new learning in relation to the intervention, which led to concrete "tangible dyadic changes."

Conclusion(s): Together, these dual studies highlight the tailored and unique supportive care being developed for the YWBC population. Individually, Study 1 provided a descriptive review of the interventions that currently exist that were developed from hospital-based and community-based paradigms. Study 2 identified the mechanisms which account for successful outcomes following participation in the Couplelinks intervention with implications for other couple-based programming for this population.

# Dedication

*For Jade Amy*

# Acknowledgements

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## Table of Contents

# List of Tables

**Chapter 1:**

**Chapter 2:**

# List of Figures

**Chapter 1:**

**Chapter 2:**

# Chapter 1

## General Introduction

Globally, women receive breast cancer (BC) diagnoses more than any other cancer site. In 2018, Canada ranked the 23rd highest country in the world for BC, based on disease rates standardized for age (World Cancer Research Fund, 2018). According to the most recent Canadian Cancer Society statistics, BC accounts for 25% all new cancer cases in Canadian women, which corresponds to approximately 27,700 women being diagnosed each year (Canadian Cancer Society, 2021). The lifetime probability of a woman in Canada developing BC is currently 1 in 8. Also within Canada, BC is the 4th leading cause of cancer deaths, preceded by lung cancer, colorectal cancer, and pancreatic cancer (Canadian Cancer Society, 2020). In Ontario, it has been found that women of Chinese and South Asian descent have differences in stage-related diagnoses. For example, women of Chinese background are diagnosed at earlier stages, and women of South-Asian background are diagnosed at later stages, both relative to the general population of women in Ontario (Ginsburg et al., 2015). In a study conducted in Manitoba, women of First Nations descent were more likely to be diagnosed at later stages (stages III-IV) and had higher mortality rates compared to all other women from Manitoba (Decker et al., 2016). Population-based studies in countries similar to Canada, such as the United States and the United Kingdom, have also found disparities in BC stage and survival rates based on demographic factors like ethnicity, socioeconomic status, and immigration (Ginsburg et al., 2015). In the United States, White women are more likely to be diagnosed with BC; however, Black women are more likely to die from it. The mortality rate per 100,000 women is 27.3 for Black women, whereas it is 19.6 for White women (National Cancer Institute of the NIH, 2017).

One high-needs subgroup of BC patients intersecting with these geographic and ethnic disparities, are those diagnosed at a relatively young age. Although Canadian women diagnosed between the ages of 30-59 years, for example, account for 38% of the total BC population (Canadian Cancer Society, 2021), younger women are disproportionately more likely to experience considerable distress as a result of the disease (Muzzatti et al., 2020). Importantly, there are barriers to accessing support resources for young women with BC (YWBCs).  In a landmark study of YWBCs from across Canada, titled 'Nothing Fit Me', 65 YWBCs who had been diagnosed at or before age 45, expressed their unmet needs (Gould et al, 2005). Participants referenced concerns with sexuality, loss of fertility, access to fertility-preserving treatments, a lack of information with respect to breast reconstruction, romantic relationship distress, and life-stage interruptions with work and family (Gould et al., 2005). Fundamentally, many of their concerns are tied to relationship-relevant issues. In the years since the 'Nothing Fit Me' report was published, there have been several investigators and community support programs that have attempted to address the scarcity of psychosocial resources for YWBCs. This dissertation examines YWBC programming in two contexts: Firstly, those available in community and hospital settings, and secondly, in an intervention designed expressly for YWBCs and their partners. The first study offers a birds-eye view of supportive care in a North American context that exists to date, and the second hones in on a specific, empirically-validated intervention for YWBCs and their partners called Couplelinks, developed in the Psychosocial Oncology Laboratory at York University (Fergus et al., 2021). More specifically, the first study provides an overview of the YWBC supportive care landscape of both research and community-based programs, which includes a discussion of each domain's praxis and theoretical models, and how their differing praxis might affect the availability and uptake of their respective programs. The second study examines the poor versus successful outcomes in Couplelinks. Both studies, together, offer opportunities to understand and further develop interventions tailored to this unique group—as follows from the recommendation of YWBCs themselves who have noted the significant gap in their age-related needs within their BC care (Gould et al., 2005).

## Characteristics of Breast Cancer by Age

The study of early-onset BC is a relatively ‘younger’ field of biological and psychological science. Since an individual’s age is typically treated as a potential confound rather than as a modifier variable in RCTs, stratifying by age was overlooked for some time in BC research (Anderson, 2009). However, the more modern rationale for division of BC research by age is a sound one because younger women are different than their older counterparts with respect to tumour characteristics, treatment preferences and recommendations, and psychosocial needs (Shoemaker et al., 2018; Ahmad et al., 2015; Anderson, 2009). Now that age stratification is utilized in research, YWBCs are defined in the literature as those diagnosed under the age of 50 years (Narod, 2012). YWBCs are increasingly studied as a sub-group among women with BC, when it comes to investigating tumours, age-specific treatment, and psychosocial needs and interventions. Thus, women with BC are often divided into age categories of below 50 years or age 45 - 50 years and above. This stratification is commonly employed due to postmenopausal status typically occurring after age 50 (Narod, 2012). There are some researchers who further classify and make distinctions among YWBCs as a group, with classifications based on “relatively early onset disease” (between ages 40-49 years) and “very-early onset disease” (under age 40) (Narod, 2012). In the past decade, in the US, there has been an increase in the number of BC cases in young women (Cardoso et al., 2012), yet in Canada and globally, rates of early-onset

BC have remained relatively stable in the last decade (Canadian Cancer Society, 2021; Narod, 2012).

## Prognosis of Young Women with Breast Cancer

Young age at diagnosis of BC is associated with aggressive cancers (e.g., triple-negative tumours) (Shoemaker et al., 2018). Young age is also an independent risk factor for ipsilateral recurrence and contralateral BC (Collins et al., 2012; Rubino et al., 2010). Even with early detection and treatment for this group, young women have higher mortality rates due to BC compared to women who are diagnosed in middle-age or older (Fredholm et al., 2009), whereas the opposite effect occurs for women diagnosed in middle-age, when early detection and treatment is associated with a higher 5-year relative survival ratio (DeSantis et al., 2019; Fredholm et al., 2009). YWBCs are more vulnerable to treatment delay given that they are screened infrequently, which is assumed to be due to both screening delay and tumour biology. These factors have been hypothesized as the main reasons for poorer prognosis among YWBCs (Fredholm et al., 2009); (the mechanisms of BC screening are explained below). Racial disparities also exist. Young Black women, American Indian, and Alaskan Natives in the United States have the highest proportion of later-stage tumours at diagnosis compared to White, Asian or Pacific Islander women. Black women in particular are more likely to be diagnosed younger, with triple-negative subtype, and to die from their disease compared to White women (Shoemaker et al., 2018).

As such, optimal treatment for YWBCs is a research priority. Since 1985, The Early Breast Cancer Trialists Collaborative Group has been synthesizing data from large scale randomization trials and longitudinal studies within BC research. They have found that adjuvant chemotherapy and Tamoxifen (pharmacological treatment) can reduce the mortality of women diagnosed before age 50, by up to 38% (The Early Breast Cancer Trialists Collaborative Group EBCTG Website; Peto et al., 2012). This finding is promising and has made its way into treatment guidelines for young-onset BC, but what remains unknown is if all young women should receive chemotherapy regardless of tumour status or grade. Conferring a cancer treatment like chemotherapy as a standard practice, which has a cytotoxic effect on healthy cells and fertility, requires more research and long-term follow-up, as well as risk assessments and harm-benefit ratio analyses.

## Breast Cancer Screening

BC is detected in women via screening and testing. In 1988, Canada developed its first organized BC screening program (Public Health Agency of Canada Archived Report, 2005/2006). Prior to this, asymptomatic women were not routinely screened. Today, the Canadian Task Force on Preventive Health Care has different screening recommendations depending on the individual's age. In Canada, women ages 60-69 years represent the largest group of women who receive BC diagnoses (Canadian Cancer Society, 2021), followed by the age ranges of 70-79 years and then 50-59 years respectively. The median age of diagnosis in women in the US is age 62 (National Cancer Institute of the NIH, 2017). Thus, it is recommended that women in Canada aged 50-69 years receive mammography every two to three years. Women aged 40-49 years are not recommended to undergo screening, given that the prevalence is lower in this age group. Some women prefer to refrain from screening when provided knowledge of their relative risk based on age and a lack of identified risk factors (Canadian Task Force on Preventive Health Care Published Guidelines, 2019). However, the guidelines to refrain from screening for young women do not apply to women who may be at increased risk of developing BC. Risk factors for BC and increased screening are discussed below. Following the results of a mammogram, women may be advised to undergo a biopsy to confirm a diagnosis. Overall, women are encouraged to weigh their decision-making about screening based on their values and beliefs, and inquire about the risks and benefits to screening by their healthcare providers, especially for younger women for whom screening is discretional (Pace & Keating, 2014). Some important decision-making factors for young women to be aware of include that mammography is not a perfect screening tool. Potential risks of BC screening include detection of false positives resulting in more imaging or testing, and screening may provide a noninvasive cancer leading to overdiagnosis. Magnetic resonance imaging (MRI) may be used as supplemental testing and for high-risk candidates. Experts estimate that approximately 19% of women who are diagnosed with ductal carcinoma in situ (a non-invasive mass) may undergo unnecessary treatment, given that oncologists cannot conclusively confirm if a ductal carcinoma in situ will threaten an individual's overall health or mortality (Pace & Keating, 2014). On the other hand, benefits to screening in general include the potential for earlier detection and decreased mortality, and in joint consideration with age and independent risk level. The benefits of screening are generally outweighed by the risks of screening for women who are between the ages of 60-69 and whose family history increases their risk.

## Breast Cancer Risk Factors

In understanding the risk factors that contribute to the etiology of BC, Engel's biopsychosocial model (1977) may be utilized to explain the complexity of cancer risk (Borrell-Carrió et al., 2004). Engel's theory serves to expand illness conceptualization beyond biology alone. In the biopsychosocial model, the molecular, psychological, and social/environmental context are all identified as contributing properties to illness and disease. As such, understanding BC risk is best explained by acknowledging its biological and environmental contributors. The

Canadian Cancer Society website (2020) lists a thorough overview of BC risk factors falling into all three of these domains. The following risk factors, as of December 2020, are listed. These are general risk factors and are not classified by any degree of risk (e.g., high or low risk). They include: 1) Biological/Physiological risk: BRCA gene mutations, other gene mutations (CHEK2 & PALB2), dense breasts, certain genetic conditions (e.g., Li-Fraumeni Syndrome), age (highest incidence in women ages 50-69), atypical hyperplasia, tall adult height following menopause (although the research regarding height is not confirmatory), Ashkenazi Jewish ancestry, exposure to ionizing radiation, hormone replacement therapy, and reproductive history (oral contraceptive use, age at menarche, age at first offspring's birth).

2) Social/Environmental/Contextual risk: living in a developed country, high socio-economic status, a personal history of BC, family history of breast and other cancers, alcohol, obesity, physical inactivity (Canadian Cancer Society, 2020). When it comes to increased risk for younger women, high breast density (category 4 on mammography) is significantly associated with elevated risk, as well as first-degree relatives with BC, obesity, and physical inactivity (Nelson et al., 2012; Dehmark-Wahnefriend et al., 2012; Friedenreich, 2010). To a lesser degree, yet still considered risk factors for YWBCs, there are additional risks which include: a prior benign breast biopsy result, breast density (category 3), second-degree relatives with BC, current oral contraceptive use, nulliparity, and being age 30 years or older when having one's first child (Nelson et al., 2012). There is a higher proportion of BRCA1 and BRCA2 genetic mutations occurring in young-onset BC estimated to be present in some 6-9% of cases; however, an accurate prevalence rate of genetic mutation among this group is unknown as is the genetic mutation impact on survival and treatment outcomes (Malone et al., 2000; Peto et al., 1999). Importantly, it should be noted that diagnostic trends among BC worldwide show that women

have increased risk as they age. Women are most likely to be diagnosed between ages 50-69 years (Canadian Cancer Society, 2020), which has contributed to a relative lack of research among young-onset BC.

**Distress among YWBCs**

YWBCs are generally more distressed than older women with BC and have been aptly termed “a minority group with the majority of need” (Ahmad et al., 2015, p.271). Consensus within the literature indicates that YWBCs experience greater intensity and duration of distress among the BC population, during and after treatment. Considering the effect of treatments that YWBCs undergo, this group often reports challenges with the onset of early menopause, loss or impaired fertility, difficulty with bladder control, and sexual functioning concerns (e.g., painful intercourse and vaginal dryness) (Baucom et al., 2006; Avis, Crawford, & Manuel, 2005; Kroenke et al., 2004). For fertility concerns in particular, young adults with cancer (YWBC included) are often placed into premature menopause via chemotherapy and pharmacologic treatments. For some women, menses may resume following treatment although for women who remain amenorrheic for a period of one year following treatment, they are at increased risk of premature ovarian failure and often do not resume menstruation (Rosenberg & Partridge, 2013). Canzona et al., 2021 has shown that issues with fertility can contribute to future decisional regret and amplify feelings of loss, in part due to the suboptimal dissemination of fertility-preservation care and information. In one sample of YWBCs post-treatment, some of whom had children, participants expressed that during active treatment they were focused on survival; however, they felt information and help with decisions regarding fertility was generally lacking which became apparent following their treatment (Wang et al., 2020). Furthermore, greater distress among YWBCs is linked to greater risk of mortality (Wang et al., 2020). Frustrations with the lack of information and discussions around fertility preservation have also been shown in a sample of mixed disease-site female cancer survivors (Vanstone et al., 2021). In addition to fertility concerns being a large contributor to YWBC distress, the lived experiences of YWBCs with metastatic cancer captured in one qualitative paper shows that this age group is faced with concerns about illness disclosure, professional challenges such as negotiating time off from work, contemplating the future, and finally the existential notion of living with a poorer quality of life and how to regain a sense of thriving despite such hardships (Ginter, 2020).

Clinical indicators of YWBC distress are evident from the very high proportion of psychiatric and psychological comorbidities in this group. Self-report and psychometric testing assessing depression and anxiety disorder symptoms tend to show YWBCs can meet criteria for these disorders up to 5 years post-diagnosis (Greaney et al., 2015; Howard-Anderson et al., 2012; Ruddy et al., 2013). In a recent large-scale systematic review, a significant association was found among YWBCs and being diagnosed with depression and/or anxiety (Wang et al., 2020). Post-traumatic stress symptoms (PTSS) have been shown in a large sample of YWBCs from the Young Women's Breast Cancer Study, although symptoms were not greater compared with a general BC population. In this specific study, PTSS symptoms were inversely correlated with social support and having a college degree (Vazquez et al., 2020).

## Relationship Distress

Among romantic partners, relationship difficulties due to BC diagnosis and treatment are an area of concern. When compared with other couples coping with ongoing medical or chronic illnesses apart from cancer, such as arterial hypertension, depression, and healthy controls, Salakari et al. (2017) found that those in the BC survivor and arterial hypertension groups (a comparison group) most often rely on their partners as their main source of social support. Male partners of women with young-onset BC have been shown to be highly distressed themselves (Jones et al., 2013). On the other hand, partner support and mutual coping have been implicated as helping factors and are believed to be of high value for adaptation and adjustment to BC. The accumulation of research in this area has shown that being well-supported by one's partner predicts better adjustment to cancer (Zimmerman, 2015), and that couples who communally cope during a taxing series of cancer-related events (from diagnosis, through treatment and thereafter) can experience mutual growth and relationship strengthening (Fergus & Gray, 2009; Dorval et al., 2005). Factors that may increase closeness among couples, shown in a sample of women with non-metastatic BC, included accompanying one's partner to appointments, communal coping (defined in this study as the spouse providing advice about coping with diagnosis and treatments), and an increase in affection gestures (Dorval et al., 2005). In one study, targeting the partner's distress with diagnosis and treatment led to improved outcomes for both the partner and the woman diagnosed (Jones et al., 2013). To further understand dyadic support in the coping process, Borstelmann and colleagues (2015) investigated the relationship between varying degrees of partner support and anxiety in both partnered and non-partnered groups in a sample of YWBCs. They found that two groups, (1) women who were not partnered and (2) women partnered in perceived unsupportive relationships had a higher number of anxiety symptom scores and lower perceived social support scores, compared to women in a third group of supportive partnerships who reported better perceived support and lower anxiety symptoms (Borstelmann et al., 2015).

## Interventions in Breast Cancer for YWBCs: Individual and Couple

Coping concerns specific to YWBCs are known problems that can go unaddressed (Ahmad et al., 2015), and so the development and evaluation of targeted interventions are growing. YWBCs have identified “feeling different” than older patients, and they have thus asked for survivorship supports that adequately address their unique needs, including provision of opportunities for greater contact with other YWBCs (e.g., YWBC support groups), tailored educational materials, and psychosocial counseling (Ruddy et al., 2013: Gould et al., 2005). In one study, the support needs of YWBCs were investigated in an ethnically diverse sample of women who were 42 years or younger when diagnosed with BC (Ruddy et al., 2015). Qualitative interviews among participants yielded findings in which this sample seemed to share similar needs, such as lack of support for their families, for example, managing changes to relationships with children or partners. Participants spoke of feeling alone and remedying these feelings by forming connections with other young survivors (Ruddy et al., 2015). A detailed overview of supportive care interventions for YWBCs will be discussed within Study 1.

To understand the BC couple intervention research to date, it is important to review dominant theories and recommended practices for all women with BC and their partners, irrespective of age, due to their being more research among older women given their increased likelihood for BC diagnosis. The Development-Contextual Model of couples coping with chronic illness (Berg & Upchurch, 2007) has been used as a theory-guiding framework for development of programs. This theory targets three relationship domains in structured interventions: (1) dyadic appraisal, (2) dyadic coping, and (3) dyadic adjustment. Dyadic appraisal within the chronic illness literature refers to cognitive processes, for example the way the couples interpret the stressful events of the illness (e.g., treatment). Dyadic coping in the health context refers to a “temporal process of coping with different aspects of illness management, and sequentially as coping unfolds in more discrete time moments across a conversation or over days” (Berg & Upchurch, 2007, p. 941), and two partners working together to reduce their distress (Bodenmann, 1995). Finally, dyadic adjustment, the construct we were interested in for Study 2's task analysis of Couplelinks, refers to an outcome, typically examined in empirical studies, wherein factors such as dyadic coping affects adjustment. Generally, within couples' interventions in BC, a combination of skills-training and psychoeducation for partners is recommended, with aims such as reducing partner dissatisfaction, and enhancing couple coping and couple cohesion (Traa et al., 2015). Taken together, the multidimensional health effects of BC pose major challenges for women who are diagnosed young and those close to them.

## Summary of Research Objectives

Supportive care for YWBCs requires greater attention given the heightened distress of this uniquely positioned BC population. Towards that end, this pair of studies broadly explores interventions for YWBCs, for individuals and couples.

(1) The first is a scoping review and environmental scan of YWBC interventions that exist to date in English-speaking regions. The content and availability of programs for YWBCs stemming from both the research and community domains have not been compared with one another. With these distinctions in mind, we conducted a scoping review of the research literature with the aim of identifying YWBC empirical interventions that have been academically developed and disseminated. Then, we carried out a web-based environmental scan of community-based programming and resources for YWBCs. We aimed to capture and examine both 'worlds' of researcher-led and community-led supportive care programs, as YWBCs are users of both domains. Furthermore, we looked for evidence of partnerships between the two domains, and their differing praxis, by turning our attention to their relationships and development during the searches.

(2) The second study consists of a task analysis, a psychotherapy-process method, to study the change mechanisms of an empirically-validated YWBC online couples intervention called ‘Couplelinks’ (Fergus et al., 2021). Couplelinks was developed with the lack of easy access for couple-based interventions for young couples in mind. The RCT of Couplelinks showed modest effects on positive dyadic coping after treatment. However, the mechanisms of change for this intervention remain unknown. Given that Couplelinks is the only couple-based intervention specifically designed for YWBCs that we are aware of, theory development and improvement of the intervention is warranted.

Collectively, these studies were intended to expand our knowledge of a growing area of psychosocial programing for YWBCs, by identifying what currently exists (Study 1) and to deepen our understanding of the pre-existing Couplelinks intervention and its mechanisms of action (Study 2). Each study’s distinct research objectives are further outlined within their own chapters.

# Chapter 2

## Study 1- Examining Hospital and Community Supports for Young Women with Breast Cancer in North America and English-Speaking Regions

### Introduction

Although a diagnosis for BC typically occurs in women ages 50-69 years-old (Canadian Cancer Society, 2021), younger women are not invulnerable to BC. In the BC literature, 'younger' women are defined as pre-menopausal and under the age range of 45-50 years (Narod, 2012). In the United States, YWBCs account for approximately 11% of new BC cases (National Cancer Institute, 2017). The specialized needs of younger women are salient across the cancer journey, from diagnosis, treatment, and into the survivorship years. International consensus guidelines on caring for the YWBC population note age-related gaps in care (Paluch-Shimon, 2020; Patridge et al., 2014). Since the guidelines were first released in 2014, they consistently note the lack of evidence-based standards for the YWBC group, from age-specific tumour markers, multi-gene expressions, treatments, to follow-up care. Promisingly however, the gaps identified in the literature have led to greater attention to the layered challenges that YWBCs face. Specifically, the updated guidelines recommend a multidisciplinary approach to supporting the psychosocial and life-stage requirements of YWBCs—in relation to fertility, body image, and sexuality issues –which are more pronounced in this population (Paluch-Shimon, 2020). Ongoing psychosocial assessment is emphasized, with the inclusion of partners and other family members in the individual's supportive care plan as early as possible. It has been postulated that dedication and commitment to the unique needs of YWBCs via timely, age-related supportive care[1] that appreciates and integrates life-stage factors and YWBC-specific needs will promote

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[1] Age-related care for this population is primarily fertility counselling with respect to treatment

psychosocial benefits and positive outcomes, through the avenues of increased adherence to treatment regimens, decreased distress, and improved quality-of-life (Partridge et al., 2014).

YWBCs are known to have multifaceted psychosocial needs, yet there are few, tailored supportive care options for this age group. Even with the existence of support options within both healthcare facilities and community organizations, there are barriers to access and utilization, which include competing professional and childcare demands, financial burdens, and logistical and travel time burdens (Fergus et al., 2021; Ahmad et al., 2015; Kroenke et al., 2004). Timely awareness of support options is another overlooked consideration when aiming to ensure that the resources that are available to YWBCs can reach their intended audience at an optimal time (Partridge et al., 2012). In addition, YWBCs may worry that their oncology team may not be as familiar with treating their age group, impacting the confidence they have in their providers (Young Survival Coalition Website, 2021). Moreover, efforts for streamlined care within the oncology healthcare system are essential, yet Pedersen et al. (2014) note that YWBCs and their families continue to experience barriers to receiving continuous, age-specific support within "the labyrinth of oncology care" (Pedersen et al., 2014, p.77) making healthcare difficult to navigate for this group.

One of the few studies conducted with a Canadian sample of YWBCs investigating their psychosocial preferences and the services they used found that participants identified a 'lack of fit' with the supportive care provided (Gould et al., 2005). In this study, a group of 65 YWBCs across Canada participated in focus groups. They noted that there were no pronounced barriers to accessing general information about BC, but rather resources regarding topics and concerns relevant to YWBCs were lacking, namely in the areas of sexuality, endocrine response and menopause, lymphedema, breast reconstruction, spouses and young families, and finally, lack of childcare services within the hospital (Gould et al., 2005). In this study, participants generally recommended the development of services that are age and life-stage appropriate.

We are aware that there are ‘pockets’ of supportive care for YWBCs in certain regions and online worldwide. However, we do not have a thorough understanding of the YWBC supportive care resources that cater to English-speaking regions – namely, what is being offered to YWBCs, and how and when it is being delivered in order to help this group cope with their disease. To our knowledge, there is a singular exception to this gap in the literature: a narrative review of international YWBC specialized services (Villareal-Garza et al., 2015). The authors conducted an internet search and directly contacted coordinators to clarify the programs. Of the 27 YWBC programs reviewed, Canada and the USA appeared to have the most offerings. They found that psychosocial support in both academic and community settings were diverse in their offerings, for example they identified traditional, healthcare provider-facilitated, support groups (face-to-face and online), informal meet-ups, retreats and socials, information (manuals, fact sheets, seminars and workshops, conferences, retreats), mobile apps, peer support, and support for partners, families, and children (Villareal-Garza et al., 2015). Their appraisal of these programs indicated that services often lack healthcare providers. Programs may eventually be terminated when funding expires. Furthermore, most programs are offered in developed countries where communications are delivered in English, leading to healthcare disparities for marginalized groups and for individuals for whom English is not their primary language. Uniquely, what this paper commentates on is that grassroots, advocacy groups are crucial to the sustainability of supportive programming, as they offer outreach and access to resources where gaps in the healthcare system exist. YWBC-specific care within hospitals is at risk of suspension of programs and resources, contributing to a lack of continuous care, due to lack of funding.

Even though partnerships between academic-hospital and grassroots organizations exist, the nature of their relationship has not been systematically studied and documented, and the ways in which each disseminate and provide support to YWBCs (e.g., similarities and differences in types of programming offered) have not been carefully compared. The lack of understanding of the interface between hospital and community resources may reflect the perception of disjointed care for this sub-group of women with BC. Given that YWBCs are often left 'to flounder' in the healthcare system and are often lacking suitably tailored supportive services that are sustained over time, the value of comparing these two supportive care domains is that we would be positioned to understand, compare, synthesize, and, most importantly, to streamline support services for YWBCs (whether housed within hospitals or the community).

## YWBC Supportive Care Domains

There are both researcher-led and community-led interventions and resources available to YWBCs. Interdisciplinary programs, usually found in hospitals, are typically attached to a research program examining patient satisfaction, program evaluation, and clinically-relevant outcomes (e.g., psychological distress) often through randomized control trials (RCTs) (Stephen et al., 2017; Greaney et al., 2015). At the same time, BC support is not necessarily confined to hospital settings (King, 2004). Community initiatives have led to the creation of organizations intended to support YWBCs (such as Rethink Breast Cancer based in Ontario with a national platform). It is important to recognize and study the community-based platform of support, in addition to academic research programs, because both are available to YWBCs, yet it is unclear whether they are working in concert to offer such programs and/or influencing one another with their varying types of expertise – that is, based on the lived experience of YWBCs (grassroots) or clinician-researcher understandings and caring for YWBCs (hospital-based). Fundamentally, both research and public community spheres, of which both realms are striving to meet the unique psychosocial support needs of YWBCs, function quite differently when it comes to implementing support programs. Academic institutions typically function from their scientific rigour purview and seek to empirically test their interventions for efficacy and outcomes (Clay, 2010), whereas grassroots organizations addressing patient needs, typically from outside the hospital system, have their own implementation and acceptability standards, of which we are lacking knowledge and understanding.

### Implementation of YWBC Programs and Interventions

RCTs are known as the 'gold standard' method within clinical research and this is how cancer interventions are often studied for efficacy and outcomes, whereas it is our assumption that community organizations generally operate within a not-for-profit or business model, rather than empirical model. We are (admittedly) limited in our ability to comment on the process of community organization implementation, given that we (the writers) are coming from a research environment and the knowledge we are seeking regarding community contributions to YWBC supportive care is underrepresented in the academic literature. This limited understanding of YWBC care outside academia underscores our current investigation, which is to describe the perspectives and models occurring within community organizations, in addition to the hospital-based interventions.

## Study Objectives

What is known is that hospital-based settings and community-based organizations strive to provide information and psychosocial care to YWBCs. However, the support provided through these different avenues has not been compared, making their similarities and differences unclear. The primary aim of Study 1 is to describe the YWBC supportive care program landscape from all dissemination domains, with a focus on psychological interventions offered within North America and other English-speaking regions. A secondary aim is to examine the extent to which academic and community settings engage in knowledge-sharing with one another. A third aim is to explicate the assumptive differences (e.g., praxis, development, implementation) between the two YWBC supportive care landscapes.

An assumption underlying this study is that both domains, the research world and community world, are not in sufficient communication (yet are of course not entirely separate) to facilitate adequate pooling of knowledge, toward their shared and overlapping goals of meeting the support needs of YWBCs. This assumption is concretized when one considers an individual YWBC patient: Would she have access to empirically based supportive care within the community? This question drives home the point that knowledge translation efforts do not necessarily materialize into sustainable, accessible supports for the YWBC population. A barrier to the integration of scientifically-derived understandings and community-based support is that the two YWBC support domains may be using different underlying premises and different 'languages' – i.e., empirical, hypothetico deductive premises versus a more experientially imbued grassroots paradigm. Consequently, Study 1 will not only entail a scoping review and environmental scan of both domains, but will also critically examine the distinctions and assumptions at play within the hospital realm as compared to the community realm.

## Methods

The aims of this study were to provide an overview of the range of supportive care available to YWBCs, and to investigate the relationship between academic and community domains. The study was reviewed and approved by the York University research ethics board. Data collection was organized into two, consecutive phases, given that the two domains (research and community) house their knowledge under different roofs. First, a scoping review was conducted to encompass and identify YWBC supportive care programs that have been developed, studied, and disseminated from academic institutions (hospital and university). It is our assumption, based on our experience as researchers, that the knowledge dissemination of such interventions would appear within, and be confined to, peer-reviewed journals. Therefore, we turned to database searching, using a scoping review method, within the medical and psychological fields to search for these types of studies. Second, a community-based, environmental scan was undertaken in accordance with different guidelines. Here, it was assumed that the community organization programs could be found online by accessing their web-based content. As such, we used a web-based, environmental scan combined with a grey-literature search strategy to accomplish this part of the analysis. These joint, complementary methods allowed us to gain a comprehensive sense of the interventions broadly targeting YWBCs, as well as compare the similarities and differences across the two types of programming (hospital-based and community-based).

Essentially, each genre of support necessitated its own type of search strategy: A scoping review has a defined set of guidelines to adequately survey the literature, whereas an environmental scan looks for publicly available information or sources of information that would not be found within peer-reviewed journals (Porterfield et al., 2012). Environmental scanning is frequently used within health research and government agencies (Rowel et al., 2005; Graham, Evitts, & Thomas-MacLean, 2008). While some scoping reviews can include the likes of an environmental scan, given its broader scope and inattention to methodological quality, we chose to separate the two for clarity of data collection. A combination of a scoping review plus environmental scan is an approach used within health services and the public health literature (Najafizada et al., 2021; Porterfield et al., 2011).

## Part 1: Scoping Review Methods

### *Search Strategy*

A scoping review is an exploratory process which seeks to map key concepts, types of evidence, and gaps in a particular area within research (Colquhoun et al., 2014). The process involves selection of research studies, based on specific criteria, and culminating in a synthesis of existing knowledge. Scoping studies are preferrable when a topic has not been reviewed extensively before (Arksey & O'Malley, 2005) or the body of knowledge is heterogeneous (University of Toronto Libraries A, 2020). Compared with a systematic review, a scoping review may be broader and more inclusive of the literature, less clinically driven, and is not focused on evaluating the quality of the included studies (Arksey & O'Malley, 2005). The search, selection, and synthesis of a scoping review culminates in a collated summary and categorization of the topic (University of Toronto Libraries A, 2020). This study's aims and proposed methods were registered with the Centre for Open Science (OSF) as an open-ended project on January 5th, 2021, linked here.

The development of the search strategy was guided by Colquhoun et al. (2014), PRISMA-ScR guidelines (Tricco et al., 2018), and a series of consultations with a York University Faculty of Health librarian in Summer 2020. Initially, the framework of the search was constructed using the PRISMA extension for scoping reviews guidelines (PRISMA-ScR) (Trico et al., 2018). This framework allowed for clarification and decision-making on the eligibility criteria for the search. Eligibility criteria were determined based on the research question, namely the observed gaps in the program landscape and types of interventions offered to YWBCs from community and institutional settings. The eligibility criteria for the scoping review are listed and discussed below.

After solidifying the research question(s), the search terms were selected. The snowball search method is a precursory stage where exemplary papers or ‘model papers’ directly in line with the research topic are informally used to generate a list of potential terms (University of Toronto Libraries, 2020). In conjunction, the PubMed algorithm helps to identify articles that are similar to ‘model papers’ for the topic. The snowball search and PubMed algorithm allowed us to explore and identify the appropriate search vocabulary, i.e., key words and subject terms (known as MeSH terms) to ensure an effective, all-encompassing, and appropriately targeted search (York U Librarian, personal communication, May 2020; University of Toronto Libraries, 2020).

Following the establishment of subject headings and key words, the primary researcher in this study (Shira Yufe) undertook a search of the following databases in order of their listing here: (1) PsycINFO, (2) CINAHL and (3) PubMed. York university’s research librarian advised this ordering of database searching given the research topic and the overlap and relationship between databases (York U Librarian, personal communication, July 2020).

The final, MeSH terms in the search included: “Breast Neoplasms” and “Psychological.” The snowball method to identify appropriate search terms generated these final words: “breast cancer” AND “young” OR “early onset” AND “support” OR “supportive” OR “intervention” OR “program.” The following filters were applied: “humans”, “scholarly journals/ peer-reviewed” “English language” and “January 1, 2000- Present day.” The final database searches included in the study occurred in June 2020 (PsycINFO & CINAHL) and October 2020 (PubMED).

### *Inclusion and Exclusion Criteria*

The following inclusion criteria determined the types of articles that were searched for: (1) programs designed for women with early-onset BC as defined in the literature as diagnosis before age 50, (2) support programs that were considered structured, unstructured, formal or informal, (3) comprehensive programs, defined as one or more service (clinical and/or informational). The exclusion criteria included: (1) programs for women diagnosed above age 50, (2) singular (i.e., one time) and passive informational interventions, such as pamphlets only (3) articles on psychosocial needs of YWBC alone (no intervention or program component), (4) programs originating in non-English speaking regions. We included descriptive, qualitative and quantitative studies, given the relatively small number of interventions specific to YWBCs alone – a decision consistent with the scoping review strategy of retaining different methodologies.

### *Selection Process*

Two research assistants and the primary author determined the eligibility of articles through two rounds of screening that were conducted independently. In the first screening round, the title and abstract were scanned using the eligibility criteria. To be deemed relevant, the abstract and title had to have indicated, at minimum, the presence of a BC intervention, regardless of the age of the participants. To expand the search catchment potential and increase the number of articles to search, the two research assistants ‘combed’ the references of the articles identified following the first round of screening. The study team met as a group regularly to discuss abstracts and articles and to deliberate their applicability to our review aims, and ultimately to reach consensus. In the second screening round, publications that met criteria went onto full text review by the research assistants and the primary author, independently. At this point, full articles were screened for YWBC- specific interventions. Articles were flagged for review that were not clear in meeting eligibility and were deliberated on by the research team during consensus meetings.

Once the research team became immersed in the screening, additional reasons for exclusion came to light. The following are reasons for exclusion, after the second round of screening: (1) psychosocial programs for cancer that were not site-specific, (2) mixed-sample studies of different chronic diseases (e.g., diabetes & cancer together), (3) genetic counselling interventions, (4) decision-aid programs, (5) articles that reported on the same intervention (e.g., descriptive study and RCT; in these cases, we used the trial study), (6) publications that were single case studies, reports, conference abstracts and lectures. (7). It was also decided to exclude articles that were designed for BC participants that included a sample of both younger and older BC patients and survivors. We found that many articles had a mixed-age sample, and while these types of studies are valuable for several reasons, such as greater sample sizes, accessibility, and similarity of BC experiences and treatments, these programs did not appear to be developed with YWBC concerns at their forefront. These mixed-age samples seemed to cater to topics such as exercise and fears of cancer recurrence that are not age or life-stage specific. Therefore, studies that had samples of a wider age range were deemed to be on the periphery of our scoping aims, and therefore excluded.

### ***Data Extraction***

For each database search, we developed and used a standardized data extraction form. Our extraction sheets had the following column titles, representing the information we garnered from the papers: (1) study title and authors (2) region (3) study aims (4) study design (5) intervention type (6) intervention goals & outcomes (7) evidence of community dialogue, and (8) additional miscellaneous notes. To chart the data in our results tables (see Results section), we used Hodges et al. (2011) checklist and guidelines for reporting on psychological interventions within cancer care. The cancer review literature has not had a clear or definitive way of classifying a ‘psychological’ intervention for some time, which has led to approximately 50 or more different types of interventions labeled as ‘psychological’ (e.g., expressive writing, healing touch, problem-solving, psychotherapy, psychiatric day hospital, etc.) (Hodges et al., 2011). Biomedical treatments, in contrast, are not as problematic, given their relatively concrete, controlled, and homogeneous nature compared to psychological treatments. It has thus been recommended that four treatment domains be used when charting and summarizing psychological interventions: (1) intervention content, (2) proposed mechanism, (3) target outcome(s), (4) method of delivery – which in turn guided our labeling and categorization scheme in the present review (Hodges et al., 2011). Results and outcome data were not extracted in this scoping review because our aim was to acquire a broader comprehension of how YWBCs are being supported, rather than appraise the methodological soundness or efficacy of the interventions.

## Part 2: Environmental Scanning Method

### *Search Strategy*

This study aimed to obtain a comprehensive, descriptive overview of the supportive care landscape for YWBCs. The advocacy, not-for-profit, and/or grassroots organizations that serve this population were examined with this goal in mind. Describing and articulating the YWBC supports available in this domain meant turning to their online presence to accrue passive, written information. To undertake this task, we developed an online search strategy informed by Villareal-Garza et al.’s (2015) narrative review method and specifically determining key words to guide the search. The key words and phrases we used were “breast cancer,” “young women”, "breast cancer young women's online community program", "breast cancer support", "under 50 young women breast cancer" and "online program breast cancer for young women". We used Google search engines multiple times between July 2020 to January 2021. It was noted that Google was primarily returning searches with YWBC resources from Canada, given our search location. We then attempted to expand the Google searches and to influence Google's algorithm by including the names of other English-speaking regions in the search box. This strategy coincided with our initial focus of English-speaking regions (e.g., United Kingdom, United States, Australia, New Zealand).

In addition to the above online search engine strategy, a grey literature review was conducted. A York University Librarian recommended a University of Toronto Library resource to develop a grey literature search (University of Toronto Libraries B, 2020). Through this webpage, we were able to access the 2019 Canadian government federal agency guidelines for searching health-related grey literature (Canadian Agency for Drugs and Technologies in Health) and other grey literature sources (e.g., GreyNet & OpenGrey). We also used "Duck Duck Go" (https://duckduckgo.com), suggested by the University of Toronto Library, which is a private search engine and does not draw upon a user's profile or search history while generating results.

### *Selection Process*

The study team determined eligibility based on the scoping review's inclusion and exclusion criteria. One research assistant and the primary author independently reviewed all organizations that were identified. However, we intentionally deviated from the scoping review eligibility criteria by including websites that were also general cancer support websites because YWBC programs were often subsumed in these websites. However, importantly, these organizations had to have shown a clear and defined YWBC section on their website. This is a distinction from our empirical review of the academic literature (where we excluded interventions that were general cancer support or BC support with a YWBC arm), it was important and valuable to cast our net wider in the community domain given that the organizational structure of community supports tend to be more generalized to heterogenous cancer populations (e.g., women's cancers, childhood cancers, etc.). Excluding these organizations would have meant missing resources available to YWBCs. Websites and online content that were unclear as to whether they met our eligibility criteria were flagged and discussed during consensus meetings.

When summarizing our findings, we determined categorization labels based on the types of websites we encountered. Full websites were scanned and reviewed by one research assistant and the primary author. Consensus conversations were helped to determine eligibility. The following represent our category identifiers for the environmental scan, ranging from general to specific. Ultimately, websites and organizations that did not fall into one of these five categories were excluded.

1) Cancer General. All of these organizations had YWBC resources
2) Breast. Inclusive of all ages (older and younger women specific to BC)
3) Young Cancer. All of these organizations had YWBC resources
4) Women's Cancers (e.g., breast and gynecological). All of these organizations had YWBC resources
5) Young Breast Cancer

### ***Data Extraction***

The primary author (SY) and one research assistant independently extracted information from the websites. SY reviewed each website for a second time to ensure no important information was missed. Following the first round of website screening, we did not use a coding scheme when extracting and labeling. The rationale for retaining the exact language of the websites at this step of data extraction, rather than imposing our own academic discourse, is that the range of programmatic offerings was vast, making it less amenable to categorization using academic language, for example changing the word ‘program’ to ‘intervention.’ We also felt it was important to preserve the communities’ own authoritative stance and ‘voice’, and to recognize the value of different assumptive differences and the language of the advocacy and grassroots supportive care domain. Following the initial, exploratory round of screening, we then used a descriptive approach to extract and chart the data (Arksey & O’Malley, 2005). Most of the phrasing we used for categorization naturally overlapped with website terminology, and terms such as “support groups,” “meet-ups”, “counselling” were often used on these websites. The final step involved collating the data.

The information that was extracted from the community websites included the following relevant topics:

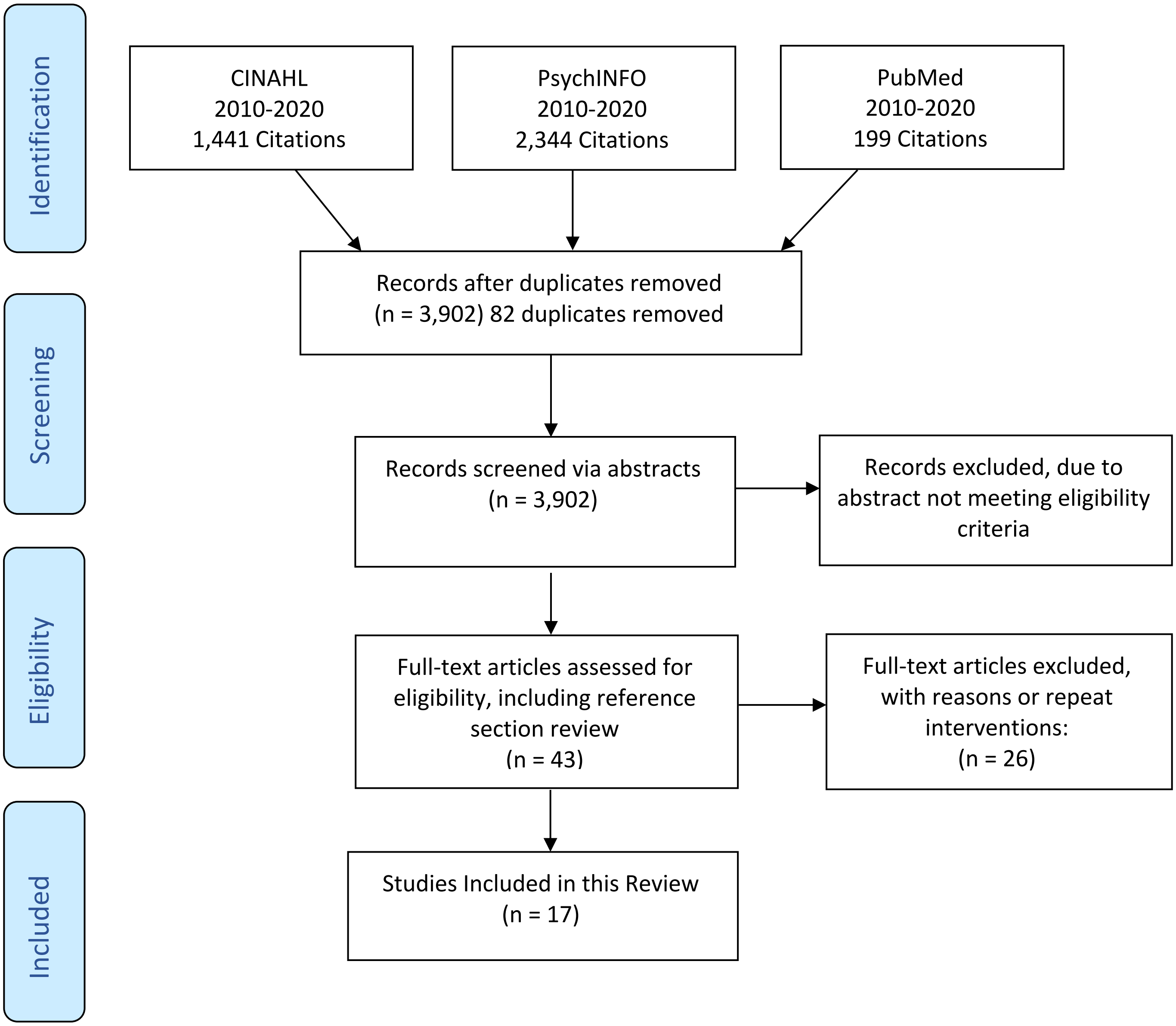
- Demographics: Name of network/organization, location
- General characteristics: disease group (e.g., breast cancer general, all disease sites, YWBC only), definition of ‘young,’ mandate or mission statement
- Resources & programming (e.g., education, support groups, recreational programs, media, statistics, etc.)
- Evidence of any relationship to research
- Presence of psychological intervention(s)

# Results

## Scoping Review Results

The search strategy yielded 3,984 citations. There were 82 duplicates identified and following their removal, 3,902 citations were screened via abstract review by two research assistants trained by the first author in reviewing citations. The total number of excluded records at this stage was 3,859 due to not meeting eligibility criteria. Forty-three articles were identified for full-text review based on the database searching and reference combing. All 43 articles were reviewed in their entirety by the primary author, of which 26 were excluded due to not meeting eligibility criteria or due to repeat interventions. If, for example, two papers reported on the same intervention, we retained the paper that reported on the randomized controlled trial where available, and if not, the article that provided the most description on the intervention itself. Included in the final scoping review were 17 studies. The PRISMA flow diagram (Figure 1) shows the selection process.

Figure 1. PRISMA flow diagram of phases of article selection.



### ***Delivery Settings & Intervention Content***

To extract the intervention content, we looked at the ‘mechanism of delivery,’ which refers to the techniques used within each intervention (as well as their theoretical orientation, and mechanism of action or change) (as per Hodges et al., 2011). In terms of intervention modality, we found that most interventions were provided via distance (e.g., virtually or via phone) (n=6), followed by a combination of in-person and distance together (n=5), in-person (face-to-face) (n=4), and unknown (n=2). What was considered ‘distanced’ included being delivered via web-based/online, telephone, text-message, or social media modalities.

We identified a range of techniques and components within the interventions. The following characterize the main features or ‘bones’ of the interventions that were present in various combinations: Education/information specific to YWBCs (n=13), social support by way of social interaction and group meet-ups with other YWBCs (n=4), shared activities (e.g., cooking, yoga, meditation) ( n=4), group counselling (n=2), individual counselling (n=2), patient or nurse navigation (n=2), survivorship care plan (n=1), and couples’ intervention (n=1). Two of 17 studies were geared to not only YWBCs but also their health care providers. Table 1 provides a summary of our findings and expands on these mechanisms of delivery and the intervention content (such as theoretical orientations, structure, outcomes studied, etc.).

### ***Study Types***

Of the included articles, we found a range of methods used to study the YWBC interventions: randomized control trials or cluster randomized trials (n= 7), descriptive (e.g., presentation of the development and/or implementation of the intervention) (n= 5), mixed-methods (n=3), program evaluation (n= 1), qualitative (n=1).

### ***Relationship to Grassroots Organizations***

We intentionally searched for evidence of a relationship between hospital-based programs and community organizations servicing YWBCs. From the outset, we recognized that this information would not necessarily be explicit, given that it is not typically reported and not a central focus of the cancer intervention literature. To extract this information, we scanned for descriptions of hospital and community-based partnerships or relationships in any form. Following this scan, we discerned a range of different connections to community organizations that served YWBCs. In some more rare cases, we observed a synthesis of both academic and community supportive care domains affording those organizations a unique position among the other supportive care interventions. These 'hybrid' programs will be further discussed within this sub-section below.

Of the final sample of 17 studies, 12 stated a relationship to a community organization. In some papers, "a community site" was referenced, although if the site was a medical oncology clinic located outside an academic centre and within a particular geographic region, we deemed this different than a grassroots organization. This was not the type of community setting we searched for.

The following categorizations speak to the different types of relationships with grassroots/advocacy community organizations and/or the functions such relationships served: 1) recruitment (n=7), 2) general collaboration or established partnership (n=2), 3) co-development of materials (n=3), 4) pooling of resources (e.g., shared physical spaces and disseminating education provided by the hospital centres) (n=3), and 5) funding research (n=1). Most studies had a relationship with the community which supported recruitment of YWBC participants for their interventions (Su et al., 2019; Ahmed et al., 2016; Fergus et al., 2014;

Germino et al., 2011; Danhauer et al., Meneses et al., 2010; Gustafson et al., 2001). Among the studies that utilized an external association for recruitment, some used more than one community organization. For instance, Su et al. (2019) recruited from several advocacy organizations such as the Young Survivor Coalition, The Susan G. Komen Foundation, and Army of Women, whereas other studies only named one organization that facilitated recruitment, and finally some mentioned recruiting through a community partner but did not provide the name of the organization.

One study tested the feasibility of a collaboration and complementary relationship between an academic medical center, regional cancer centre, and community-based agency (Danhauer et al., 2007). This cross-institutional collaboration was deemed to be enjoyable and feasible, with recognition that each partner served a complementary and unique purpose. Specifically, it was noted that the academic centre brought information about funding and healthcare providers, the regional cancer centre brought a nurse navigator to educate participants, and the community organization had stronger and wider outreach to YWBCs.

The Young Sister's Initiative (YSI), a web-based and social media program, collaborated with a community organization to develop "culturally-appropriate" (p. 2) materials and guidelines for young, African-American BC survivors (Johnson-Turbes et al., 2018). The importance of pre-established trust between users and providers of the program was emphasized for improving the development, outreach, and implementation of the YSI intervention. Similarly, Germino et al., (2013) established partnerships with community organizations to increase familiarity and trust in their program, geared to both White and African-American YWBCs.

There were some interventions born out of networks situated in a 'grey zone' or 'hybrid model' when it came to affiliation with an academic or community organization. In other words, an ‘either/or’ identity of academic OR community would not be appropriate for this small group of organizations. These programs included Sharsheret’s Thriving Again program (Rohan et al., 2018), PYNK Young Women with Breast Cancer Program (Cohen et al., 2016), and the Young Breast Cancer Survivorship Network (Gisiger-Camata et al., 2019). These networks are essentially a blend of both worlds and are located within both the hospital and community spheres. Namely, for the program Sharsheret, its roots were a not-for-profit organization which has been expanded into academia; they receive financial assistance from national funding bodies like the Centre for Disease Control in the US. In Canada, the PYNK young women’s program specializing in BC is housed within an academic cancer treatment hospital. In addition to including a nurse navigator who educates and supports each patient, the program offers structured peer-support opportunities. The Young Breast Cancer Survivorship Network aimed to institute collaborative partnerships among organizations from its inception. Outreach beyond their regional area was a major goal, and so they cast their net very wide and now have partnerships with 38 organizations affiliated with YWBC support.

## Environmental Scan Results

The web-based environmental scan of existing community programs yielded 23 organizations. These initiatives were either uniquely catered to YWBC or were general cancer or BC programs with a clear and distinct YWBC arm and/or branch of their website. All of the organizations were identified on the Internet by the study’s research assistants and reviewed by the first author and research team. Table 2 is a summary table of the organizations that were identified and deemed to meet the search criteria.

### ***Demographics***

The demographic data extraction sheet included the names of networks and organizations, YWBC specific program names, and their geographic location. Most organizations were located and operating within North America, primarily the United States (n=12) and Canada (n=4). Some programs stated that they were founded in a specific US state or Canadian province and expanded nationally or internationally. Outside of North America, we identified two organizations from the United Kingdom (UK), two from Australia, and three from New Zealand.

### ***General Characteristics of Organizations***

Of the 23 organizations that were identified, data were extracted from their websites relevant to our descriptive aims and research questions; namely (1) what types of support are being offered to YWBCs? and (2) what, if any, is the organization's relationship to academic programs? Five of the 23 organizations were dedicated solely to YWBCs. Fourteen of the 23 organizations were dedicated to general BC support and included a special section or webpage(s) on YWBCs. Three of these also catered to other women's cancers (e.g., gynecological cancers such as ovarian or cervical). Two of the cancer support organization sites were geared to young adults and contained specific pages or resources dedicated to BC. Organizations identified and labeled themselves in various ways such as a "registered charity", or "foundation", or as a "not for profit," "patient-centered," "consumer," "community" or "grassroots" organization.

### ***Supportive Care Programming***

The community-based offerings were highly varied. We labeled and categorized the supportive care resources and programs for YWBCs as follows:

- Education and information. This is arguably the largest type of support that was observed and disseminated online. It will be expanded on below.
- Direct financial support for breast health services or links to grants available to YWBCs
- Patient advocacy training and workshops
- Individual support (peer-to-peer support, healthcare provider support)
- Support groups (face-to-face, online, and through social media such as closed or open Facebook groups)
- Survivor conferences
- Activity-based or skills-based programs (e.g., Tai chi, book clubs, cooking classes)

### ***Methods of Education***

The information provided on the websites was disseminated through various education formats. We found passive forms of written or audio information (e.g., blog posts or podcast links), videos from key individuals with relevant knowledge such as healthcare professionals, patients, survivors, and BC advocates. Interactive forms of information were available within live webinars or "ask an expert" or Q&A type forums. For most websites, the education provided was embedded or directly posted to the websites (i.e., not an external link) - although many also contained links to external websites, articles, or resources with reading or educational materials (e.g., links to counselling resources or links to online clothing stores that service BC survivors). In addition to the education provided from articles or topic areas on the websites themselves, we found downloadable books or guides, book recommendations, documentaries, or app recommendations. Downloadable information would typically include BC facts, statistics, personal experiences, and/or self-paced worksheets (e.g., food, mood, or exercise tracking tools), and/or materials to be used in reference to healthcare provider visits and communications (e.g., screening tools, questions to ask your oncologist, etc.). The most common educational topics available to YWBCs included personal stories, statistics such as prevalence and incidence of BC rates among women in general and/or younger women, and research summaries and/or other knowledge translation outputs.

### ***Psychological Interventions***

Within the community organization websites, we specifically looked for evidence of psychological interventions geared for YWBCs (as per our research question). We found that some community sites offered individual or group-based Cognitive-Behaviour Therapy (CBT), Mindfulness or Mindfulness-Based Stress Reduction (MBSR), and "Psychotherapy" or "Group Support" (n=6). Psychoeducational programs were the main source of supportive care observed. Some websites offered reading materials or suggested evidence-based psychological interventions or psychotherapy, although they did not necessarily have these programs embedded within their offerings. One, more large-scale program (Sharsheret) had an in-house clinical team that was available to speak with YWBCs, as did the PYNK program which included social work and psychology professionals along with their main source of support, the nurse navigator.

### ***Relationship to Research***

In the same vein as the empirical scoping review, we searched for evidence of a relationship to research and/or academia within the community organizations. What was observed were different connections to the research world and to varying degrees of intertwinement.

The following categorizations indicated a research relationship: mention of a partnership with an academic institution (n= 2 ); naming research priorities (n=3); links to academic literature and research articles available on the website (n=8); study notices with recruitment announcements and the ability to sign up as a potential research participant - via hyperlinks to clinical trials and other studies (n=2); knowledge translation - via summarizing research papers in lay language or interactive media (n=3); directly funding research projects from their own organization's grants or foundation (n=1); research centers and laboratories housed within an organization conducting independent research (n=1); research agendas, such as advocating for inclusivity and diversity within YWBC research (n=1); and training patient advocates to participate in patient-centered research as patient advisors (n=1).

Similar to the 'either/or' identity that characterized a small subset of the hospital-based programs (see Sharsheret for example), some community supportive care programs appeared to be more embedded in its hospital-based partnership, thus pointing to the 'hybrid-style' of programming that we also observed in the scoping review. For instance, The Susan G. Komen (USA) organization has several affiliated researchers and states that they provide funding for research. The Breast Cancer Now organization (UK) cites research partnerships with academic institutions, and also provides funding and scholarship opportunities through their fundraising. These less-common community-based programs do not necessarily fall into a black-or-white categorization. Although they may be located within the community and appear to be born from a grassroots foundation, they also appear to have significant research-based arms and may be engaged in providing empirically-supported care to YWBCs, although it was not the norm to see direct evidence of such programs through the website.

## Discussion

This study aimed to delineate the supportive care available to YWBCs in English-speaking regions. Together, the scoping review and environmental scan captured the ways in which YWBCs may gain access to psychosocial services; it also offers a compare and contrast analysis of the two support worlds. In the published literature, while there are scoping and systematic reviews dedicated to explicating the psychosocial *distress* of the YWBC population, they have not focused on YWBC-specific interventions that target their age group (Recio-Saucedo et al., 2016). Therefore, this scoping review endeavoured to fill a gap by describing the range of supports available to YWBCs with a focus on psychological interventions that exist, as well as the content within such interventions and their method of delivery. Using a multi-method searching approach, we found that resources dedicated to YWBCs (and their loved ones) are not confined to hospital-academic settings. There is a vast world of support that exists within the YWBC community outside healthcare institutions. Thus, this study considered the entirety of what is being offered to YWBCs within both healthcare and community settings. Importantly, this research documented a mutualistic relationship between hospital-based and community-based, grassroots organizations.

The scoping review identified 17 empirical interventions designed and implemented for YWBCs. This age-specific set of interventions is promisingly sizeable, among a literature that appears to be saturated by interventions that are designed for women with BC in general, unrelated to participant age. The unique stressors of YWBCs, such as fertility concerns, body image, sexual concerns, and feeling thwarted before life goals may be obtained (e.g., professional goals) are scarcely addressed in such interventions, thus more tailored supportive care is needed if a wider age range of participants is present within a given study.

During the article selection phase, it came to light that a substantial portion of the BC psychological care interventions were not for YWBCs alone. Rather, we found that most studies that appeared in the first review phase were ultimately geared towards women with BC in general and included a large age range in their samples (e.g., ages 18-79 years). In considering why a large age range might be the norm among research for BC interventions, it stands to reason that greater age inclusion is important not only to adequately power statistical analyses and improve generalizability of findings, but also to provide services to a greater number of individuals where the demand is needed. One research paper we had originally flagged to move to phase 2 of evaluation discussed the differences between their younger and older BC participants within their couple-based BC intervention (Kayser et al., 2010) (although ultimately this paper was not included in our review given it did not meet the age selection criteria). Still, the 17 psychological interventions identified in our review indicate that researchers and clinicians are responding to the call to address the unique life-stage of young womanhood and BC diagnosis and treatment within BC supportive healthcare (Paluch-Shimon, et al., 2020; Ahmad et al., 2015). We observed an influx of YWBC interventions in the literature between 2008-2017. Prior to this, we found one study published in 2001.

We found that information and education are emphasized in hospital-based programs. These programs tend to be accessible by distance education (e.g., web-based, social media, text messaging). Online uptake of information among women with BC is high (Bender et al., 2013), and the feasibility of online support has been shown among YWBCs who display a preference for flexible and accessible information, given their time constraints and familiarity with technology (Ahmad et al., 2015; Owen et al., 2004). One systematic review of YWBCs undergoing mastectomy or breast-conserving surgery found that YWBCs require an abundance of information, “both in content and volume” (Recio-Saucedo et al., 2016, p.12), even if they rely on their oncologists to influence their treatment decision-making. Five of the 17 studies we identified specifically provided education on reproductive health and fertility following treatment, which YWBCs consistently state is lacking. One of the studies measured attention to fertility concerns among oncology providers (Greaney et al., 2015). Women of child-bearing age who are diagnosed with cancer (breast and other gynecological cancers) have expressed their need to discuss their menstruation, contraception options and their future fertility, and be supported by their providers with not only adequate information and decision-making with fertility choices as they relate to BC treatment, but also psychological support in navigating this territory (Besse et al., 2010; Peate et al., 2009).

Apart from the informational emphasis of YWBC programs delivered in hospitals, we observed a heterogeneous array of additional services within hospital settings under the umbrella term of ‘psychological’ interventions. While some studies entailed YWBC programs that were educational alone, others were geared towards skill-building and/or teaching coping strategies. The types of therapy orientations and skills we found included: concrete problem-solving strategies, mindfulness-based skills, cognitive therapy for mood and anxiety symptoms, addressing fears of recurrence or body image concerns, and improving overall quality of life. Tips for managing common symptoms due to treatment were provided, for example coping with hot flashes, or sexual changes such as vaginal dryness or sexual dysfunction (e.g., dyspareunia). We found a similarly substantial emphasis on education for YWBCs within the community agencies. There were many overlapping informational topics between websites for YWBCs, namely symptoms of treatment, sexuality, fertility, fears of recurrence, genetics and hereditary cancers, and survivorship. Interestingly, there were resources available within the community -

specifically on coping with a BC diagnosis (for example “the newly diagnosed navigator tool” which came from The Young Survivor Coalition), although we did not observe the topic of ‘coping with diagnosis’ within hospital-based interventions. The discrepancy here could be due to timing of interventions being after diagnosis and treatment, or hospitals being more focused on getting YWBCs through their active treatment (which could be time-consuming with chemotherapy and radiation schedules for example) before addressing psychosocial concerns. The exception was one hospital-based intervention specifically designed for coping with uncertainty (Germino et al., 2010). Overall, it appears that the supportive care landscape for YWBCs, in both hospital and community settings, are centered on educating this group and providing information-based resources related to common side effects and psychosocial concerns related to age. In this way, it is a reasonable claim that the interventions and programs available are catered to YWBCs’ unique needs.

Several differences observed between the academic and community offerings were the presence of anecdotal patient and survivor profiles on the community websites, and the higher proportion of support groups that were promoted within community spaces. An exception to the narrative dominance we saw in the community is the PYNK program in Toronto, ON—an example of the ‘hybrid-style’ supportive care program with a hospital-community partnership. PYNK includes YWBC voices within their programs, although not by profiling survivor stories on their website. Rather, membership on the PYNK development committee is multidisciplinary and includes YWBC patient advocates (Cohen et al., 2016). PYNK includes peer support for incoming patients from trained peer supporters who are from the YWBC population. Interestingly, different styles of disseminating information were greater within the community; they offered informational videos, podcasts, and expanded outside their individual reach by providing links to external sources. Whereas the education provided to research participants, observed within the scoping review, was limited to educational tools offered within a singular intervention. Both educational styles (i.e., multiple educational modalities versus a single medium) may be valued depending on the young woman with BC. Some may prefer a plethora of information, while others may be best served by one, targeted source of information or intervention because they are looking for specific topics that are relevant to them (i.e., just fertility) or they could feel overwhelmed by too much information. Young women coping with BC are not uniform in their information-seeking needs or behaviours (Recio-Saucedo et al., 2016). From the perspective of conducting research, a singular intervention is most plausibly related to ensuring that all participants receive the same, controlled intervention without any confounding variables.

Within the scoping review, we found three, uniquely positioned programs that had a 'hybrid-status' of being both hospital & community based. The Young Sisters' Initiative (YSI) (Johnson-Turbes et al., 2018), PYNK (Cohen et al., 2016) and Thriving Again housed within Sharsheret (Rohan et al, 2018). These are program models that have a hand in both domains. Sharsheret, for example, is a non-profit organization servicing women with breast and ovarian cancer and their families. They sponsor research and have healthcare professionals within their organization. In their own organization description, this joint membership is emphasized. As well, Young Sisters' Initiative is a partnership where the researchers worked with a community organization that had a pre-established level of trust among African-American YWBCs. The developers of the YSI commented that this partnership helped with promotion and program development that would feel appropriate and sensitive to cultural understandings of YWBCs. These two examples of hybrid programs (PYNK and Thriving Again from Sharsheret) were represented in both the academic literature and community channels, whereas Young Sisters' Initiative was not found in the environmental scan search. Although the relationship between academic and community domains was more intertwined than initially expected, the lack of grassroots and/or non-profit organizations found within the scoping review (as compared to the environmental scan) points to ways in which the academic literature could be more expansive and inclusive in relation to how supportive care is offered. Granted, the purpose of the hospital-based YWBC studies may be to 'test' interventions and not necessarily to establish them outside the hospital. Still, there is room for greater accessibility of community understandings of YWBC supportive care for researchers in hospitals not just by way of recruitment, given that it represents a substantial portion of psychosocial care that YWBC patients are obtaining and utilizing.

The web-based, environmental scan was a natural progression from Villareal-Garza et al.'s (2015) narrative review of specialized programs for YWBCs. Their earlier review paper found many supportive care programs outside of the academic literature. In our online environmental scan, we found 15, new supportive care organizations/websites that were not profiled in their study. Their geographic breakdown of the community programs showed most programs exist within the US, and that many programs are not YWBC-specific (five of 23 community organizations). The latter findings are comparable to what was seen in the current scoping review of the academic literature wherein many interventions targeted BC in general irrespective of age, yet there were a surprising number of stand-alone, YWBC-specific interventions. The fact that there are more BC supports for women of all ages reflects the global prevalence rates of women with BC, i.e., the fact that there are more older women (after age 50) who receive and survive BC diagnosis worldwide (Narod, 2012). Apart from updating the 2015

Villareal-Garza's et al. review paper, we combined the web-based environmental scan findings with the scoping review and compared both supportive care domains, descriptively and interpretively. Thus, the current review adds breadth and comprehensiveness to what is already known, while commentating on the relationship between the two support domains. The present analysis allows clinicians and patients to understand the interventions and programs available to YWBC, how accessible these programs are and for how long. A tertiary implication of this study is that each domain may consider if it is worthwhile to engage with the other and further enhance their mutual relationship.

While academic and community organizations resembled one another in their strong emphasis on education and providing communal spaces where YWBCs would be brought together to support one another in their shared experience, the community sites differed with respect to their psychosocial support. Some community sites, for example, offered financial aid (e.g., Sharsheret, Shocking Pink, Young Pink Sisters), and this form of support was unique to community-based supports. In addition, patient advocacy trainings, survivor conferences, and a variety of activity-based programs were held and promoted. In general, it appeared that community organizations had a blend of formal (in-house counselling or referral sources) and informal support ('hangouts', drop-in yoga, or cooking classes), whereas academic programs had more structured support with defined parameters (e.g., 10-week program with different, educational or skills-based modules assigned each week), and sometimes a healthcare professional facilitator(s). Activities such as yoga and art, although not classified as 'psychological interventions' have been shown to be therapeutic and assist with coping, and positively improve the quality of life of women with advanced BC (Willis et al., 2014). One study which investigated the phenomenological experience of young women under age 40 with incurable metastatic BC found a ‘differentiation’ process “between [just] living and living well” (p.429), wherein participants found relaxation and a sense of hope from coping-skills activities like yoga and meditation (Ginter, 2020) which enabled them to live well, not just simply survive. Thus, the plethora of activity-based programs that are seen within community organizations and the mindfulness programs that are available in hospital-based centres is substantiated by emerging research.

When it comes to the relationship between empirically-developed interventions and community-developed programs for YWBCs, there appears to be a mutualistic relationship between these development domains and overlap in their priorities. The most distinct similarity between the two spheres was the emphasis on education and keeping YWBCs informed about their treatment options. For example, as previously discussed, the need for giving YWBCs’ fertility-related materials was represented in both domains. Peate et al., 2009 concluded that education on fertility is preferred *before* YWBCs begin their adjuvant therapies (e.g., chemotherapy, radiation, hormonal medication), and the community educational resources on fertility that are widely available online can fulfill the time expectation to receive said information. While some, although not the majority, of community organizations already have oncology healthcare providers who act as consultants for resource and information development, more community organizations and their YWBC users might benefit from having this consultancy available to them. One consideration is we could not fully comment on hospital and community relationships because the mention of “partnership” or “affiliation” alone did not provide enough information on the nature of their relationship. These terms are commonly used, but what is meant by “partnership” in practical terms is rather opaque. Future studies may seek to explicate this relationship further (perhaps by conducting interviews in conjunction with website and literature reviews) in order to illuminate the inter-relationships between health care providers and community groups, and to encourage more solidified and clear partnerships between support domains.

Although we have delineated a clear division between two supportive care domains for YWBCs (1) hospital-based and (2) community-based, they are not always mutually exclusive and thus it is worthwhile to clarify their overlap for both patients and providers. This study shows that both researcher-led interventions and community-led programs exist for YWBCs, albeit through some similar and different avenues and methods of support. The intersection and overlap between the two domains are findings corroborated by our scoping review and environmental scan. Yet, as expected, the two YWBC support domains harbour, and function within, different paradigms, ‘languages,’ and practice models. Prior to data collection for this study, one of our assumptions underlying the scoping review was that the two domains are not in sufficient communication with one another (yet are of course not entirely insular) to facilitate adequate discussion and pooling of knowledge, towards their shared and overlapping goals of meeting the support needs of YWBCs. However, the results of the scoping review and environmental scan yielded a more complex, multi-dimensional relationship between the supportive care domains that may be best described as a ‘mutualistic relationship.

### *The Nature of the Mutualistic Relationship*

**Partnerships.** A finding from this study was the established pre-existing partnerships of community and academic support programs for YWBCs. There was evidence of co-development of materials, although this was seen sparingly. Within the hospital-based world, we found some studies asking for assistance from community stakeholders to implement their studies and establish “buy-in” from potential participants, often enabling large-scale recruitment efforts.

Within the web-based community world, we saw academic affiliations that were less obvious as to what exactly the “affiliation” entailed. One limiting factor in describing the various modes of partnership was that we could not obtain details of these partnerships from websites alone, although it was clear that some community sites had developed and/or were connected with some researchers as they explicitly named their research affiliations. While we maintain that there exists a mutual relationship between the two, it is not necessarily a reciprocal relationship. The mutual-nonreciprocal relationship is discussed in the following section.

**Membership & Recruitment.** Recruitment for research participants stood out as a major factor that holds the relationship between the two domains together. There appears to be high uptake of the community-based supports in the YWBC population. We often noted that recruitment flyers for research studies were listed on community websites, which indicates that researchers are aware of the potential to expand their recruitment efforts within the community. To obtain an informal sense of how many YWBCs might be engaged with community organizations, we looked at examples of publicly available, basic social media metrics. The Rethink Breast Cancer Organization, founded in 2001 with its headquarters located in Toronto, Ontario, has a Facebook page detailing the organization’s activities. A public search of this Facebook page conducted by the author on May 4, 2021 showed 32,159 individuals “following” this page. What is meant by “following” on Facebook is that users can see updates and posts from that page (Facebook, no date available, (n.d.A)). Depending on the nature of the individual user’s Facebook account settings, individuals may receive ‘pushed’ updates that automatically appear on their personal Facebook accounts, or they are able to manually navigate to an organization’s page. As well, we looked at another community organization called Bright Pink, located in Chicago, United States. It was founded in 2007 and it cites its ‘community impact’ online. They offer a risk assessment tool for breast and/or ovarian cancer and their website states that “over 600,000+ have learned that they have a possible hereditary risk” from this tool (Bright Pink, 2021). They state that their online support community connects more than 1,300 people. In contrast to these relatively large number of YWBC users and individuals who are engaging with the YWBC support community, the interventions housed within hospitals studying efficacy and clinical outcomes may find it comparatively harder to access the same number of YWBC individuals (often for recruitment purposes) (Paluch-Shimon et al., 2020). For example, the Young and Strong RCT (Partridge et al., 2019) enrolled 467 participants recruited from 54 academic or community sites across the US. Taking into account the research context, this particular study has a large sample, relative to a more typically-sized sample within the YWBC literature, such as the Mindfulness Meditation RCT for YWBC, which had a sample size of 71 participants (Bowers et al., 2015). The Young Sister’s Initiative study, identified within the scoping review, is a stark exception in its sample size (1,442 visitors to its website), although this study’s intervention is more easily accessible online and positioned itself within the community. What we have gleaned from our data collection is that the foremost unifying factor across the two domains is that researchers seek out the YWBC population engaging within the community to ‘furnish’ their studies and accrue larger samples to power their analyses, whereas it appears that the understandings gained through scientific rigour (e.g., psychological interventions developed and tested) are not necessarily being implemented through the community channels that provide research participants for the academic studies.

**Empirical Interventions in the Community.** What was observed within the community support domain was that these organizations would connect their membership to research, mainly through advertisements on their websites. It was not the norm to see empirically-studied programs housed within the community, whereas less formal educational resources and open support groups or “meets-ups” dominated the community web-based space. We found 1-2 group, mindfulness-based and/or CBT programs being offered, and a limited number of counselling services or referral options through the community organizations. The conclusion we derived from observing a lack of empirically-based psychosocial programs is that the offerings and understandings gained through scientific rigour are not necessarily being disseminated, as we did not see mention of ‘evidence-based’ or ‘best practice’ programs. We might hypothesize that efforts to provide evidence-based interventions from the hospital-based channels to the community may be absent due to lack of funds to hire mental health professionals to mount or run these. However, it is also conceivable that there are differing paradigms or missions within the community that may not be compatible with ‘hospital-like’ programs. Despite the lack of evidence-based programs in the community, the research world and the studies being conducted within it are made available via community channels for individuals who wish to participate or access published research.

**Operation and Functionality.** Functional differences were observed between the two supportive care domains. Research and public community spheres, of which both realms are aiming to meet the unique psychosocial support needs of YWBCs, appear to operate quite differently when it comes to praxis. At the development stage, hospital-based institutions typically plan and execute from their scientific method purview and seek to empirically test their interventions for efficacy and outcomes (Clay, 2010). Interdisciplinary healthcare programs are typically attached to a research program examining YWBC patient satisfaction, program evaluation outcomes, effectiveness trials and RCTs (Nicolaisen et al., 2017; Stephen et al., 2017; Greaney et al., 2015). RCTs have been brought into question and been studied microscopically for their benefits and weaknesses (Walker, 2005). Clay (2010) notes the main issues with RCTs have to do with sample sizes and a trade-off between striving for internal validity and losing external validity. For example, biochemical effects (e.g., pharmacology studies) trialed in humans tend to be *less* varied among individuals whereas psychological interventions typically interact with factors such as sex, gender, age, socioeconomic status, etc., and therefore there are tight eligibility criteria for enrollment (Clay, 2010). Furthermore, the RCT process can take years to recruit a large enough sample size and can be dependent on funding (Kersten et al., 2010; Westen et al., 2004).

In contrast, community organizations may be functioning from a not-for-profit, grassroot association (GA), or business model. Of the three, GAs are the most ubiquitous, thus herein, we attempt to explicate the internal structure and processes of GAs and their historical underpinnings to BC supportive care. An earlier term for grassroots was “membership or voluntary association” (Horton Smith, 2010). Horton Smith (2010) claims that GAs are generally distinct from paid-employers or registered non-profits because they come from blended business-charity models. GA ideology is one of solidarity. Within cancer, they are often founded by an individual who has had cancer or by a family member or caregiver, such as the Susan B. Komen Foundation (Tovey et al., 2007). Membership tends to increase in size over time (Horton, 2010), given that there are few prohibitive bounds for entry and participation of members. GAs tend to organically draw a distinct, homogeneous group of individuals with a common and shared disease and illness experience. In the book “The Politics of Breast Cancer” (2001), Casamayou writes about how the early history of grassroots BC organizations is associated with BC political activism and the lobbying efforts of the National Breast Cancer Coalition (NBCC) founded in 1991. The NBCC advocated for research funds dedicated to BC research (Casamayou, 2001).

The NBCC is well-known for its “Do the Write Thing” Campaign in 1991 where they garnered 600,000 letters detailing the personal suffering of American women with BC and their families (and the tremendous loss of life due to the disease) that were sent to Congress in Washington, DC. The success of some AIDS grassroots movements had inspired similar advocacy initiatives to effect change and include the voices of patients within government and healthcare (Casamayou, 2001). More generally, in the cancer support world, patients and family have long explored alternatives outside of a biomedical approach. For example, complementary and alternative medicine (CAM) and holistic approaches, such as Reiki, acupuncture, massage therapy, and holistic approaches are common and may be preferred, specifically to heal from the side effects of chemotherapy and pharmacological effects (Tovey et al., 2007).

What was unanimously observed among the GA websites in our environmental scan were patient voices and narratives. It appears these GAs make substantial efforts to amplify the stories of the young women and individuals coping with cancer. Patient voices are congruent with Lober and Flowers (2011) concept of the rise of the “e-patient”; essentially an individual who is technologically-enabled and who is empowered throughout their healthcare journey through their use of the Internet. E-patients are typically associated with younger cohorts who are more aware of patient-centered care, unconsciously or not, and who use the internet and social media to remain engaged, feel heard, and express their healthcare needs via story and testimony. In one study looking at pregnancy and postpartum experiences among young, female cancer survivors, the participants felt the strain of substantial gaps in pregnancy-related information during and after cancer treatment, which led to an emboldened position of searching for information outside of their immediate healthcare circle (Vanstone, 2020). As well, investigating online survivor testimonies to learn about patient experiences has been done with a sample of prostate cancer survivors (Zanchetta et al., 2016). Therefore, it may be beneficial to continue to study YWBC experiences via e-patient stories, considering the plethora of availability and the sense of comfort that younger women may have with detailing their experiences online. Moreover, social media and cancer support is a vast world that has not been explored in this study, although it warrants investigation in the YWBC population, who are well-versed and high utilizers of the technological world for healthcare information.

**Sustainability.** What the community-based organizations may be able to offer over the hospital-based interventions is a continuous flow of supportive care to YWBCs that is not time-limited from identification of needs to providing programs to fill those needs. Firstly, the community may be faster to produce tangible offerings and availability, as they are not constantly testing or examining their supportive care via time-consuming research projects. We might define this mentality of GAs as ‘doing and acting’ over ‘testing and trying.’ The cautiousness of the research world means that what is offered is evidence-based, but the trade-off is that it may not be fast enough to meet the needs of YWBCs or provide an uninterrupted supportive care experience. Secondly, the lack of continuous funding for hospital-based interventions means that programs may be halted, contributing to disjointed care for YWBCs. Ruiz-Casado et al. (2018) identified themes that threaten the lack of sustainability in cancer care programs in hospitals, by interviewing interdisciplinary cancer care providers. This study found that the absence of support (practically and implicitly) from managers in institutions, and a general lack of both time and funding contributes to lack of sustainability of multidisciplinary programs and opportunities for educating providers within cancer care. A large-scale report from the National Academy of Medicine on improving quality of cancer care within the U.S. healthcare system makes the point that psychosocial support is rarer in general, especially during diagnosis and treatment, because it is “usually supported through ad hoc philanthropic funding rather than institutional or clinical practice resources” (Institute of Medicine, 2013, pg. XI). In sum, the empirical method paradigm (which has relatively longer timelines combined with fragile, often finite funding) in contrast to the community paradigm (which has relatively faster timelines) is what sets the two apart when it comes to program sustainability.

The programs which are blended and have established solidified partnerships (Thriving Again, PYNK, Young Breast Cancer Survivor’s Network) and appear in both internet searches and the academic literature might be recognized as model programs for YWBC supportive care. Their level of integration seems to span across research, education, and patient advocacy. Both realms coalesce around their shared expertise that they each bring to the table. Although a valuable stamp of approval of this blended program model is best given by the YWBCs themselves, we believe that YWBCs may benefit from such hospital-community alignment for a number of reasons. For instance, we may see increased research participation from YWBCs, and YWBC research priorities being taken up by the academic-hospitals, since YWBC voices tend to be stronger within community spaces and can make their way into research priorities and research design vis a vis a patient-centered care model. In evaluating the Young Breast Cancer Survivor’s Network, Gisiger-Camata et al. (2019) highlight the growth capacity of such academic-community partnerships. A major strength of this program’s model is the sustainability of their programming, given their high level of funding. It has been noted that one of the biggest challenges of YWBC support programs is that continuity of funds is deficient, which abruptly sacrifices program availability and puts both patients and providers alike in precarious situations (Villarreal-Garza et al., 2015), where providers lose employment and patients experience abrupt cessation of services. Within Thriving Again, the developers have managed to remain sustainable until now, which is helped by strong community support and engagement of users, and capacity to expand to additional US states and accrue continuous flow of funding from different regional sources (Gisiger-Camata et al., 2019). Nevertheless, even for academic and community programs that appeared to be more insular and function independently (i.e., without partnerships), we were still able to see a relational appreciation between the two support domains, and occasional capitalization of resources from one source to another. One short-term intervention hosted their workshops at different community locations and participants were invited to go to the setting closest to where they lived (Bloom et al., 2008). Such pooling of spaces is but one concrete example of creating a connection between hospital and community for the benefit of both domains, which ultimately benefits YWBCs.

## Limitations and Future Directions

This study is not without its limitations, and future directions are discussed in light of these. In both the scoping review and environmental scan, we did not gather qualitative data by interviewing program founders or directors, to be able to fill in up-to-date information. For example, when "counselling" was listed on a website it was unclear what this entailed (e.g., what type of provider (peer or type of professional), modality, or theoretical orientation). We wondered how the developers themselves might define their hospital -to- community relationship and vice versa. Also, websites can be outdated and may not detail every program that they offer to YWBCs, or alternatively, may list programs no longer being offered. The same informational deficiency may have occurred within the research papers we identified within the scoping review wherein aspects of the intervention that were relevant for our review such as developmental framework or theory were not reported. In this research, the assessment of hospital and community resources would have benefitted from qualitative interviews with stakeholders and developers, which could provide a more comprehensive picture of their approach and philosophy to YWBC supportive care apart from their mission statements often available online. To broaden our web-based search and ensure we 'caught' as many relevant community organizations as possible among the vastness of the Internet, we used grey literature search techniques and varied our search terms. Still, we feel that relying on internet searching and websites alone may have limited our capacity to locate all organizations. Many of these organizations have a large social media presence and may have provided additional information on their social media, such as through Instagram, Facebook or Twitter that we did not obtain in this study. Another limitation to consider is that we targeted both hospital and community psychosocial support from English-speaking regions, which means we do not have a good understanding of YWBC supportive care where English is not the dominant language. Future studies should look for examples of YWBC supports in other regions. Finally, a suggested future study in this area is a systematic review of YWBC supportive care where methodological rigour and efficacy of interventions could be evaluated.

## Conclusion

Overall, this study provides a scoping review in conjunction with an environmental scan to describe the supportive care resources that are offered to YWBCs through academic institutions and grassroots organizations. Our primary aim was mapping and describing what is the current state of YWBC supportive care available from all sources. Then, understanding the programmatic similarities and differences allowed us to learn from each knowledge source. While academic and hospital-based programs were more likely to offer empirically supported psychological interventions such as cognitive-behaviour therapy (CBT) and mindfulness, community organizations were more likely to provide informal social support and practical assistance (e.g., childcare and finances). Both hospitals and community programs focused heavily on education. Interestingly, what we found was more of a communal relationship between the two domains than what was anticipated, namely in terms of resource-sharing, complementary roles, and interdisciplinary teamwork. What was also identified was a hybrid-style program model that included both domains bridging their resources together. In essence, we have seen a conjugal affiliation between both domains, despite their differing praxis. The results of this study provide an overview that is broad and inclusive, and of potential value to academic readers, community networks, clinicians, and YWBCs themselves. Having access to a comprehensive overview of resources allows those searching for YWBC support to know what they are receiving, how likely it is to last, and to what extent the support offered is evidence-based, informational, and/or practical. This research may also instigate hospital-to-community partnerships and vice versa that are sustainable and blend both worlds harmoniously, for the ultimate benefit of YWBC psychosocial support models.

Table 1.

*Synthesized results table of YWBC interventions*

| First Author & Date | Intervention Name | Region of Development | Intervention Content | Structure and Mechanism(s) | Study Type/ Outcomes | Delivery Setting | Relationship to Grassroots Organizations |
|---|---|---|---|---|---|---|---|
| Ahmed et al., 2016 | Life After Breast Cancer Intervention (LABC) | Los Angeles, USA | Education<br>Group Counselling | All day workshop with 2 distinct modules | Pilot study; Mixed methods evaluation<br>No formal outcomes<br>Broadly investigated fears of recurrence, relationships, self-reported levels of knowledge, confidence | Academic centers<br>Community health clinics | YES<br>Co-development of materials |
| Allen et al., 2002 | The Home Care Guide for Women with Breast Cancer | USA | Education<br>Problem-solving (emphasis on positive coping) | Home care training model<br>Two in-person & at-home sessions, four telephone sessions | Randomized control trial<br><u>Outcomes:</u> rehabilitation needs, quality of life, unmet need for assistance, psychological reaction to distressing events (cancer) and social problem-solving | Private oncology practices, hospital oncology department, university oncology clinic | NO |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| Bower et al., 2015 | Mindfulness Awareness Practices | California, USA | Education<br>Mindfulness<br>Activities: (meditation, exercise) | Six-week mindful awareness intervention, two hours each week | Randomized control trial<br>Outcomes<br>Primary outcomes: Perceived stress and depressive symptoms<br>Secondary Outcomes: fatigue, sleep quality, musculoskeletal pain, menopausal symptoms and cancer specific distress | Medical center | NO |
| Bloom et al., 2008 | No specified name | USA | Education<br>Social support<br>Activities: (exercise) | Six-hour workshops over three-month period | Randomized control trial | Community locations | YES<br>Pooling of resources |
| Cohen et al., 2016 | PYNK | Toronto, Canada | Nurse navigator is responsible for ensuring that consultations take place: fertility, genetics, or plastic surgery) | Nurse navigator | Descriptive<br>Evaluation | Oncology clinic in a hospital | NO |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| | | | and provides informal support, information & advice to patients & families<br>Education<br>Peer Support program<br>Individual counselling | | | | |
| Danhauner et al.,2007 | No specified name | North Carolina, USA | Education<br>Social support<br>Activities (relaxation exercises, physical exercise) | Six, in-person group sessions<br>Single session seminar | Mixed methods program evaluation<br>Outcomes: Quality of life, emotional distress (conceptualized as depression and negative affect), and psychological well-being (conceptualized as positive affect and satisfaction with life). | Academic medical centers, regional cancer centers and a community-based cancer support agency | YES<br>Partnership |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| Fergus et al., 2014 | Couplelinks | Canada | Couples' intervention | Six education and activity-based modules, delivered online | Descriptive Evaluation | Web-based | YES<br>Recruitment |
| Germino et al., 2013 | Younger Breast Cancer Survivor Uncertainty Management Intervention | North Carolina, USA | Education | CD containing Cognitive-behaviour therapy strategies<br>Text-based guide (on managing uncertainty and treatment side effects) | Randomized control trial<br>Outcomes:<br>1) Uncertainty management, cognitive reframing and problem solving, knowledge self-disclosure, sources for helpfulness of information, uncertainty.<br>2) Breast cancer specific concerns: fear of recurrence, intrusive thoughts, symptoms<br>3) Positive psychological outcomes: affect, personal growth, self-efficacy | Rural and urban clinical community setting | YES<br>Recruitment<br>Pooling of resources |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| Gisiger-Camata et al., 2019 | Young Breast Cancer Survivors Network | USA | Education (workshops, website materials)<br>Social Support | Individual meetings with patients<br>Outreach programs<br>Social support | Descriptive<br>Evaluation | Community Organization<br>Web-based | YES<br>Partnership<br>Recruitment |
| Gustafson et al., 2001 | Comprehensive Health Enhancement Support System (CHESS) | USA | Education<br>(decision making tools, support services) | CHESS staff provide brief training, user manual provided | Randomized control trial | Web-based | YES<br>Recruitment |
| Johnson-Turbes et al.,2018 | The Young Sisters Initiative (YSI) | USA | Education (geared to African-American YWBCs): genetic testing, coping with emotional issues around diagnosis and treatment, sexual and reproductive health issues, talking to family about BC, dating after BC | Downloadable workbook | Mixed method, program evaluation<br>assess implementation and fidelity<br>barriers and facilitators and explore audience access, use, and perceived value of the YSI | Web-based | YES<br>Recruitment<br>Co-development of materials |

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| Meneses et al., 2010 | Fertility and Cancer Project | International | Education, delivered online (reproductive health and fertility) | Education modules<br>Message forums<br>Opportunities to interact with research team | Descriptive<br>Outcomes: knowledge of fertility, experiences accessing internet information, perceived information and support from oncology providers | Web-based | YES<br>Recruitment |
| Partridge et al., 2019 | Young and Strong | USA | Education, delivered via print and/or online | Education | Cluster randomized<br>Outcomes:<br>Primary: Attention to fertility<br>Secondary: Attention to genetic issues; Psychosocial concerns | 14 academic sites and 40 oncology medical centres | NO |
| Partridge et al., 2012 | Program for Young Women with Breast Cancer | USA | Education and outreach (for YWBCs and providers)<br>Research | In-person and take-home materials | Descriptive | Academic and teaching hospitals | YES<br>Funding research |

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| | | | Referral resources<br>Individual and group psychological support (e.g., social worker) | | | | |
| Pedersen et al., 2014 | Patient Navigation | Canada | Patient navigation with oncology nurses and social workers | Health professional navigator | Descriptive<br>Qualitative | Outpatient Cancer Centre | NO |
| Rohan et al., 2018 | Thriving Again | USA | Survivorship kits: (activities, education, and interactive tools)<br>Education | Customizable survivorship kits | Evaluation | Community Organization | YES<br>Co-development of materials<br>Recruitment<br>Pooling of resources |
| Su et al., 2019 | Web-based Survivorship Care Plan | USA | Education (for YWBCs and providers) | Web-based & text message prompts | Randomized control trial<br><u>Outcomes:</u><br>(1) hot flashes, | Web-based | YES<br>Recruitment |

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| | | | | | (2) fertility-related concerns<br>(3)contraception<br>(4) vaginal symptoms | | |

Table 2.

*Summary Table of Environmental Scan Community-Based Organizations (by region)*

| Organization | Location | Disease Group | Programming and Resources | Psychological Intervention | Relationship To Research |
|---|---|---|---|---|---|
| Breast Cancer Network | Australia | Breast | Care kit (including feminine undergarments given to women following breast surgery), online journey tool which provides evidence-based information and insights from other survivors, chat rooms and information guide | No | Research articles available |
| Young Pink Sisters (Australia) | Australia | Young Breast Cancer | Virtual support groups, financial assistance | Yes-Support Groups | Not identified |
| Canadian Breast Cancer Network | Canada | Breast | Educational forums for patients and caregivers, training workshops, educational retreats and online webinars Information about, psychotherapy and psychiatry, journaling and support groups | No | Not identified |

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|---|---|---|---|---|---|
| Rethink Breast Cancer | Canada | Young Breast Cancer | Yoga and wellness treat, Facebook group, drop-in groups | Yes- Psychotherapy | Research articles available |
| Team Shan | Canada | Young Breast Cancer | Information, downloadable booklets, fundraising events, links to other sources | No | Recruitment<br>Research articles available |
| Young Adult Cancer Canada | Canada | Cancer General | Survivor conference, big cancer hook up (national event providing opportunities for young adult survivors and supports together in their local communities and connect), activity based groups, retreats, online chat rooms and webinars<br>Facebook group, retreat, etc | No | Recruitment |
| Breast Cancer Aotearoa Coalition (BCAC) | New Zealand | Breast | Links to other sources, online forum, stories from other survivors | No | Knowledge translation (not updated from 2014) |
| My BC | New Zealand | Breast | Diary to track exercise, happiness, energy levels, symptoms and food diary, webinars, | No | Not identified |

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| | | | articles, personal satirizes, educational events by nurse and group chat | | |
| Shocking Pink | New Zealand | Young Breast Cancer | Financial assistance, online support groups, helpline, resource book which includes products and services to make 'cancer journey easier and more stylish', survivor stories, information for supporters | Yes-Journaling, blogging, counseling, online support groups | Research articles available |
| Breast Cancer Now | United Kingdom (UK) | Breast | Online courses/programs, support groups, peer counseling, Q&A forum | No | Founded a research charity "Breast Cancer Now Toby Robins Research Centre" , research partnerships, funds research and sets up the "Generations Study" project to help understand cause of BC, set up "Tissue Bank", which collects processes and store samples from patients for research purposes, various research labs, and research news room |

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| Support Connection | UK | Women's Cancer | Informative webinars, articles written by professionals in the field, support groups, helpline, one-to-one peer counseling, tai chi, book club, drawing, meditation, yoga, wellness class, cooking class. | No | Not identified |
| Bright Pink (US) | United States (US) | Women's Cancer | BC assessment risk quiz, medical blog, articles, early detection card, online community, peer to peer support and professional support | No | Research articles available |
| Breast 360 | US | Breast | No programming, only informational resources | Yes- Mindfulness-Based Stress Reduction, Cognitive based therapy and exercise | Research articles available |
| Dr. Susan Love Foundation | US | Breast | Webinars, books, blogs, educational articles | No | Facilitating BC research, recruiting participants for clinical trials |
| FORCE Facing Our Risk of Cancer Empowered | US | Cancer General | Educational information, survivor stories, webinars, peer navigation program, helpline, online forum, webinars, peer | Yes- "Care provided by mental health professional" | Research tool matches prospective participants with research studies in which they qualify for. |

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| | | | navigators and local support | | FORCE Research Advocate Training: designing relevant patient-research studies. |
| Living Beyond Breast Cancer | US | Breast | Educational videos, webinars, conferences, interactive programs, ask the expert series social media groups, online and in person support groups | No | Videos, podcasts and articles regarding clinical research and clinical trials |
| Share Cancer Support (US) | US | Cancer General | Expert led educational programs (e.g., webinars), blogs, publications, helpline, support groups, link to apps for people with metastatic BC, survivor-patient navigation, online social networking groups | No | Knowledge translation |
| Sharsheret (US) | US | Women's Cancer | Educational information, pamphlet, Q&A, survivor stories, nutrition technology expert platform, 24.7 chat support, financial assistance, webinars and book club | No | Links to clinical trials and research papers |

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|---|---|---|---|---|---|
| Sisters by Choice (US) | US | Breast | Summary of research findings<br>Financial aid for breast health service<br>Coping activities | No | Links to research papers |
| SurviveDAT | US | Young Breast Cancer | Medical services, financial assistance, genetic counseling, expert advice modules resources for patients and families and friends | No | Knowledge translation |
| Susan G. Komen Foundation | US | Breast | Helpline, financial assistance, podcasts, sharing stories and hearing survivors' stories, online tools and resources (educational videos, screening tools, translated resources, interactive learning tools) | Yes-Psychotherapy, evidence based treatments, mindfulness meditation, CBT, exercise, music therapy and stress management in a group program | Funding research grants and clinical trials |
| Young Survivor Coalition (US) | US | Cancer General | Facebook co-survivor group and "virtual hangouts" | Yes-Counseling by mental health professional | Founded the "YSC Research Agenda" which is a collaboration among scientists, researchers and physicians who strive to 'end the disease' |

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|---|---|---|---|---|---|
| Young Women's Breast Cancer Awareness Foundation (US) | US | Young Cancer | Survivor stories, grants, links to other BC programs/events, support groups, patient navigation program | No | Not identified |

Legend for Disease Groups:
1) Cancer General. All of these organizations had YWBC resources
2) Breast. Inclusive of all ages (older and younger women specific to BC)
3) Young Cancer. All of these organizations had YWBC resources
4) Women's Cancers (e.g., breast and gynecological)
5) Young Breast Cancer

# Chapter 3

## Study 2- Comparing Good versus Poor Outcomes in Young Couples Participating in the Couplelinks Online Intervention Following Breast Cancer

### Introduction

Prior to the 1990s, cancer and other chronic illnesses were viewed as a stressful experience for the individual alone. Partners of individuals diagnosed with cancer, or patients and partners together, were less likely to be researched or provided with clinical services to address the psychological impact of the diagnosis and illness (Bodenmann, 1995). Today, couple distress and partner distress are commonly recognized and thus studied (Duggelby et al., 2014). An awareness of the interpersonal processes at play between partners coping with adverse live events has led to the conceptualization of 'dyadic coping.' The construct of dyadic coping has its origins in the fields of social psychology, stress research, and relationship research (Kayser & Acquati, 2019; Bodenmann et al., 2019). Interpersonal coping with illness extends beyond social support; it is a relational perspective that frames cancer in particular as a "we-disease" (Kayser et al., 2007, p.404). Bodenmann (1995) first defined dyadic coping as a bi-directional, joint process of two partnered individuals working together as a unit to reduce distress, both individually and relationally. Dyadic coping as a construct has since been differentiated into component parts. These sub-components include: a collective understanding of adverse life events (e.g., illness) and the stress it brings; couple reactivity; cognitive and behavioural strategies between and within the couple; and meaning-making of the negative experience (Kayser et al., 2007). With respect to receiving a BC diagnosis, effective dyadic coping has been shown to positively impact the female partner's adjustment to BC, while a lack of coping efforts and inadequate support between partners can impede psychological adjustment to BC (Borstelmann et al., 2015). The benefits of positive dyadic coping have been demonstrated in couples coping with other cancers such as prostate and lung cancer (Traa et al., 2015). Relatedly, the concept of relationship adjustment and/or relationship functioning, defined to include couple ‘consensus, cohesion and satisfaction’ as measured by the Revised Dyadic Adjustment scale (R-DAS) is often studied in tandem with dyadic coping (e.g., Fergus et al., 2021; Kayser et al., 2007). Importantly, positive dyadic coping is, for the most part, associated with higher relationship adjustment and thus has become a focus of researchers and clinicians seeking to enhance relationship outcomes where one partner is ill (Traa, et al., 2015). Despite relatively recent advancements in the study of dyadic coping, our understanding of the processes that lead to positive outcomes between and among couples in which cancer is a part of, and shaping of, their relational reality, is still emerging. Therefore, the broad purpose of this study is to examine the mechanisms underlying dyadic change processes in an online, relationship-enhancement program developed for a YWBC population.

The identification of interpersonal processes that occur in cancer has prompted intervention researchers to focus on harnessing and improving dyadic coping, for both in-person and online intervention formats (Hu et al., 2019; Vanstone & Fergus, 2020). These interventions often integrate theoretical frameworks of shared relationship stress, namely systemic-transactional coping— a theoretical parent to the concept of “we-ness”— (Ahmad, et al., 2016; Bodenmann, 1995), the Developmental-Contextual Model of couples coping with chronic illness (Berg & Upchurch, 2007), and most recently, relational-mutuality coping (Kayser & Acquati, 2019). Within the global concept of dyadic coping which is most often employed when studying couples in cancer, the construct has been divided into two sub-domains: 1) positive dyadic coping (emotion-focused and problem-focused) and 2) negative dyadic coping (superficial, hostile, ambivalent, and avoidant) (Bodenmann et al., 2019). Within the systemic-transactional model, the related construct of ‘common dyadic coping’ refers to congruence in adverse-life event coping perceptions. In one recent study, researchers looked at whether common dyadic coping impacts psychological distress within BC (which the researchers defined as partners supporting the other in their individual coping or engaging together in joint coping by defining the cancer as a “we-disease”) (Meier et al., 2019). They found that high congruence of common dyadic coping, defined in this study as the extent to which partners agree on how they cope dyadically, was related to lower psychological distress among female patients with BC, but not their male partners (Meier et al., 2019). Another recent study which examined relational mutuality (the ability to be empathic to one’s partner), with a sample of 86 women treated for non-metastatic BC, showed that presence of relational mutuality between partners was positively associated with common and positive dyadic coping and negatively associated with avoidance of dyadic coping (i.e., negative dyadic coping) (Kayser & Acquati, 2019).

An important consideration with respect to couple functioning in relation to BC is the female partner’s age at diagnosis. There exists a differential effect of poorer quality-of-life and strained dyadic coping for younger couples when compared with their middle-aged counterparts (Acquati & Kayser, 2019). ‘Young’ age to receive a BC diagnosis is considered to be age 50 or below (Narod, 2012). Compared to older couples, younger couples experience more pronounced negative changes as a result of cancer psychologically, physically, sexually, professionally and economically (Shahi et al., 2014; Vanlemmens et al., 2012). For example, concerns over the effects of premature menopause, infertility, body image, sexuality, and disruption to career and relationship trajectories prominently exist as stressors for this group (Howard-Anderson et al., 2012). Furthermore, young age is an independent risk factor for more aggressive cancers, BC recurrence, and mortality (Collins et al., 2012; Rubino et al., 2010; Fredholm et al., 2009). These age-related differentiating factors culminate in a highly distressed YWBC population, and these levels of distress may be maintained up to three to ten years after diagnosis (Ahmad et al., 2015; Avis et al., 2005). In contrast, this degree and duration of distress is not observed among couples who are older at time of diagnosis and with longer relationship histories (Acquati & Kayser, 2019; Ahmad et al., 2016). Fundamentally, the literature demonstrates that younger couples facing BC, both individually and dyadically, are more vulnerable to experiencing elevated and prolonged distress.

Studies have found that young, male partners experience poorer quality-of-life (up to 1-year post-diagnosis) and unique caregiving burdens when their partner has breast and/or gynecological cancer (Duggelby et al., 2014; Lopez et al., 2012). In addition, adequate support for young partners is often lacking, especially when dependent children are part of the family structure (Corney et al., 2016). Young male partners have been shown to cope differently than middle-aged partners. For example, more illness intrusiveess and hostile dyadic coping is associated with young-male age and having a partner with BC (Acquati & Kayser, 2019). The individual psychoosocial needs of young partners are becomng increasingly recognized and relevant, not only for one’s persnal functioning, but also with resepct to communal dyadic coping.

Given that coping concerns specific to YWBC and their partners are known problems that often go unaddressed (Ahmad et al., 2015), the development and evaluation of targeted interventions has become a priority. It has been observed that the “generic prescription to talk openly” for couples affected by cancer has not necessarily provided useful direction for future research (Badr, 2017, p.143). This overly general recommendation has left gaps when it comes to the structure, content, timing, and processes of intervention offerings to couples, with a marked knowledge chasm in couple interventions specific to YWBC. Couple interventions in cancer in general and BC in particular offer psychoeducation and communication training for partners, with aims such as reducing partner dissatisfaction, and enhancing couple coping and couple cohesion (Blais et al., 2015; Dorval et al., 2005). Online, couple-based interventions are also increasingly appealing, as they address access barriers and allow for greater flexibility, especially for younger couples who are often pressed for time, for example with their childcare demands (Vanstone & Fergus, 2020; Ahmad et al., 2015). Importantly, international consensus guidelines for the biological and psychosocial care for YWBCs dating back to 2014 have continually stressed the layered challenges of this group (Patridge et al., 2014). The guidelines recommend ongoing psychosocial assessment including partners and other family members in the individual's supportive care plan as early as possible (Paluch-Shimon et al., 2017). The most recent 2020 guidelines on follow-up care for YWBC added this statement: "…couple-based psychosocial interventions should be promptly proposed if needed." (Paluch-Shimon et al., 2020, p.681). It is now well recognized that more research attention should be paid to adopting a couple-based approach to supporting young women affected by BC when they have intimate partners, with the intention of incorporating such advancements into routine clinical care. Our study is responsive to this need through the examination of processes that account for improved relationship outcomes in an empirically-validated, YWBC couple-based intervention using a task-analysis method (Greenberg, 2007).

## Couplelinks

The scientist-practitioner team in the Psychosocial Oncology Lab at York University developed a novel intervention, called Couplelinks, to offer psychosocial support to young couples via a custom, online platform. Couplelinks was designed to address an observed gap in couple interventions among a younger cohort of women diagnosed with BC. Most of the couple research in BC and associated support programs are geared towards women above the age of 50 because older women are more representative of the BC patient population. Existing couple programs don't necessarily account for age during development and testing for outcomes. Considering age-related needs (e.g., losses such as compromised fertility; interruption to career and family goals) and the notion that BC erodes the strength and functioning of romantic relationships, the conceptual framework of the intervention was founded on the idea that "the stronger the relationship bond and the more well-adjusted the couple, the more able they will be to respond constructively to the challenges posed by breast cancer" (p.3, Fergus et al., 2011). As such, the tasks of the intervention are directed towards building relationship strength and resiliency. The intervention entails six, experiential, 'Dyadic Learning Modules' (DLMs), plus one optional module, for the couple to complete together within an 8-week timeframe. A professional facilitator is assigned to each couple, whose role is to orient the participants to the program, provide feedback, and offer guidance around issues as these arise via an asynchronous, text-based discussion board. The facilitator's position is ultimately one that aids in the couple's independent learning process rather than one of active intervention akin to a traditional couple's therapist (Fergus et al., 2011). The interactions between couple and facilitator include an introductory phone call, followed by two pre-arranged 'check-in telephone' calls (after DLMs #2 and #4), while all other correspondence between couple and facilitator occur in the text-based 'Dialogue-Room' located within the Couplelinks website following completion of each module. Participants interact with their facilitator in the dialogue rooms and exchange asynchronous text-based messages regarding logistics of the intervention (e.g., related to progress on the modules, or to ask questions about the program or instructions). At the end of each DLM, participants were prompted to provide general feedback about their experience, whether they liked the module, and degree of perceived benefit. For example, they were asked questions such as, “What was your reaction to the exercise,” and “Did you discover anything about your relationship or yourselves as a couple because of this exercise? If so, what did you learn?” In addition, some modules asked the participants to provide text-based responses as part of the exercise or experiential component. For instance, in DLM #3, called ‘Creating Connection,’ following education about relationship bids and ‘turning toward and turning away behaviours,’ participants were asked to reflect on their relationship behaviours and then asked to log key relationship incidents and to describe how these impacted themselves or their partner.

Couplelinks was researched in two iterations: (1) a single arm, pilot study (2009-2010) (Fergus et al., 2014), (2) and a two-arm, RCT (from 2011-2016) (Fergus et al., 2021). The initial pilot testing of the intervention examined treatment satisfaction based on post-treatment interviews in a sample of 16 couples (Fergus et al., 2014). Qualitative findings revealed benefits and limitations of the intervention, which were addressed in the later iteration of the program, specifically to improve interactivity and engagement (Fergus et al., 2015). A series of studies on “therapeutic facilitation” in Couplelinks (Carter et al., 2015), and promotion of participant engagement (Ianakieva et al., 2016; 2019) examined the relatively novel role of online couple facilitation and “eBehaviours” employed by facilitators to encourage engagement. A task analysis of online engagement (Ianakieva et al., 2016) revealed how the facilitators approached their role working with couples, and the techniques used to maintain and encourage active participation. Facilitators managed three types of relationships to foster couple engagement: (1) facilitator to couple, (2) intervention to couple (i.e., program adherence), and (3) between coupled partners (Ianakieva et al., 2016). Importantly, the two-arm, RCT findings in a sample of

67 couples were published in 2021. Treatment outcomes studied included positive dyadic coping using the Positive Dyadic Coping composite sub-scale of the Dyadic Coping Inventory (Bodenmann et al., 2006), relationship adjustment and satisfaction as measured on the RDAS (Busby et al., 1995), and the Kansas Marital Satisfaction Survey (KMSS) (Schumm et al., 1986), and depression and anxiety as measured on the Hospital Anxiety and Depression Scale (HADS-D) (Johnston et al., 2000). A non-standardized measure was developed for this study by the research team, the Breast Cancer and Relationship Measure, which captures the couples' self-perceived ability to collectively cope with BC.

Results from the Couplelinks RCT showed a small effect in the change direction of positive dyadic coping for the treatment group from baseline to post-treatment (effect not maintained at follow-up), and a small significant change on the Breast Cancer and Relationship Measure. There were no between-group effects for relationship adjustment and satisfaction, and depression; there was a significant decrease in the anxiety subscale of the HADS-A in the waitlist group from baseline to post-treatment, and a decrease in anxiety in the treatment group from baseline to follow-up (Fergus et al., 2021). The authors note that because couples did not improve on relationship adjustment despite the couples in the sample being only slightly above the cut-off for marital distress (i.e., there was room for couples to demonstrate improvement), this outcome remains an important one for further investigation. Specifically, examining the differences between couples who demonstrated improvement on relational adjustment on the R-DAS and those who did not could offer insight into ways Couplelinks could be modified to support the more distal goal of facilitating relationship change (in addition to improving dyadic coping ability). Such an analysis could also shed light on couple-factors that yield improved relationship adjustment outcomes from the program.

## Study Objective

On the research agenda within the field of dyadic coping in the cancer context is to evaluate which couples may benefit from couple-based interventions (Badr et al., 2017; Traa et al., 2015). The present study's objective is to investigate what accounts for 'good' versus 'poor' outcomes among couples who participated in the Phase III Couplelinks intervention trial. In this study, we are focusing on change mechanisms following the RCT findings, striving to understand how change (or limited change) occurs within couples participating in an online psychoeducational intervention developed for relationship enhancement after BC. In the Couplelinks context, 'relationship enhancement' is defined as consisting of improved relationship satisfaction, general relationship adjustment, and dyadic coping outcomes. Given that Coupelinks involves an array of therapeutic tasks, we are seeking a more detailed understanding of change events that may have led to observed differences in the outcome measure of relationship adjustment (i.e., the R-DAS). In so doing, we will be better equipped to identify more precise mechanisms that may account for successful versus unsuccessful outcomes from the intervention. Moreover, by comparing different outcomes, we can develop a conceptual model, that then may inform future directions for online couple facilitation and intervention.

## Methods

The Couplelinks study was reviewed and approved by research ethics boards at all its Canadian host institutions: Sunnybrook Health Sciences Centre and York University in Ontario (ID#300-209); QEII Health Sciences Centre in Nova Scotia (ID#2010- 357); the British Columbia Cancer Agency (ID#H10-00300); and Cancer Care Manitoba (ID#2013-017). Informed written consent was obtained from participants prior to enrolment into the study.

## Task Analysis

Task Analysis (Greenberg, 2007; Pascual-Leone et al., 2009) is a mixed-methods strategy used within psychotherapy research. When applied to a relational dyad undergoing an intervention, task analysis would essentially deconstruct the processes, in sequential order, of what occurred within the dyad that led to a successful or unsuccessful prototypic change (or no change). A detailed understanding of a participant or dyadic performance is uncovered and helps to explain therapeutic change. The overarching aim of the task analysis is to describe "phenomenological facets involved in the change process" (Pascual Leone et al., 2009 p. 535). The change process is understood via a 'reverse engineering' series of steps, beginning with the outcome and working backwards to identify mechanisms of improvement. A classic task analysis typically consists of two phases, a discovery phase and validation phase, following the selection of prototypical cases to closely examine (see case selection below). The discovery-oriented phase involves three component steps: (1) the creation of a *rational model,* following a set of groundwork and foundational preparatory efforts, that is based on the researcher's knowledge of the phenomena which may be rooted in clinical experience as well as familiarity with the empirical and theoretical literatures; (2) the next step within the discovery phase is to develop an *empirical model,* in which the phenomenon is organized into coherent categories in a process of abductive, category development; (3) finally, both models are synthesized to create a *rational-empirical model* which yields a rich description of processes of the tasks involved in the intervention. There is a second, validation phase of task analysis, and the purpose is to validate the discovery-oriented models through hypothesis testing in the interest of predictive modeling. This study focused on the discovery phases of model building only. The validation phase involves using new data with different participants who took part in the same intervention to verify the first phase, and to execute quantitative analyses on the qualitative model. Figure 1 shows the step-by-step task analysis process applied in the present analysis.

### ***The Discovery Oriented Phases***

Step one: This phase began with the selection of the six cases under study (See *Successful and Unsuccessful Case Selection* section below). Then, the researchers constructed a 'blueprint' of specific dyadic process hypothesized to improve relationship adjustment through the intervention. To do so, relevant affective and cognitive components of couples' participation in the intervention were identified. In this analysis, we used data sources that were previously collected within the RCT to investigate these affective and cognitive components (described below under Step 3). All the data sources were asynchronous, text-based elements of the intervention (as opposed to capturing the couples' interaction with one another or the facilitator in synchronous, real time).

Step two: The researchers then made explicit their 'cognitive map' (Greenberg, 2007), which is their perceptions, assumptions, prior knowledge, and expectations of how the population under investigation may experience change or move towards a particular outcome. The purpose of explicating the researchers' cognitive map is to disclose the assumptions from within their implicit knowledge, which contributed to the observational lens and framework of the hypothetical, rational model.

Step three: Next, the environment in which the task occurs was defined and explained. *The Couplelinks intervention is the environment*. The sources of data used for our analysis included: 1) the Dialogue Room correspondence where facilitators and participants asynchronously 'conversed' in text (typed transcripts of their text communication); 2) the DLMs (modules) themselves where participants inputted text-based responses related to the experiential components of a specific exercise (e.g., inputting adjectives describing their partner's strengths); and finally 3) the module feedback provided by participants at the end of each module via an online questionnaire administered once the module was complete.

Step four: Rational Modeling. Constructing the rational model is a conceptual understanding of what experts predict drives the change or no change, and the factors that contribute to successful and unsuccessful cases participating in a psychotherapy intervention (Pascual-Leone et al., 2009). It represents an educated 'starting point' based on theoretical knowledge and clinical experience (Ianakieva et al., 2016). In this study, the practitioner-scientists who developed Couplelinks who have expertise in designing and delivering interventions in psychosocial oncology for couples assisted the principal author in her conceptualization of the rational model. In the present study, the practitioner-clinicians would pose this question to themselves: 'How do I think couples derive benefit from participating in the Couplelinks intervention?' The responses to this speculative question initiates development of the rational model, leading to a hypothetical map of the component parts leading to benefit or no benefit. The rational model is hypothesis-generating and is used to compare, and eventually synthesize with, the data-driven, empirical model (Greenberg, 2007).

Step five: Empirical Modeling. In this study, the objective was to discern the steps involved in improved relationship adjustment outcomes derived by participating in Couplelinks. To do this, all hypotheses generated in the rational model were put aside. Construction of an empirical model involves 'observing the couples' via the data that were collected in the Couplelinks RCT. The data are then analyzed using a qualitative content analysis. The data sources that were used within the empirical modeling included: the (1) text-based Dialogue Room correspondence between couples and facilitators; (2) the module data within the DLMs;

and (3) module feedback. Greenberg (2007) suggests that the three successful cases (in this case, couples) and their progression through the intervention are investigated first and foremost, and then the three couples who were not successful are examined together as a group. Testing three cases per group is the suggested number for a manageable yet deep investigation of change mechanisms (Greenberg, 2007).

The primary author derived categories and themes emerging from the data sources pertaining to each couple. Categories were initially coded for the successful cases describing a pathway toward benefit. Data that were not relevant to or did not contribute to success or benefit were marked as 'tangents,' whereas data extracts with evidence that the individual or couple changed or moved toward benefit were captured (Greenberg, 2007). This process was continued within the successful group and later in the unsuccessful group until discernible patterns emerged that distinguished between the couples who benefitted (in terms of improved RDAS scores) and those who did not. Each case was compared within its own group to ensure a clear pattern was present. In this phase, we removed non-essential elements of the rational model that did not prove to be useful in describing the change process. The successful cases and unsuccessful cases were then compared to further investigate, question, and solidify distinguishing features. The categories and themes were shared with members of the Couplelinks research team (Dr. Karen Fergus and Dr. Saunia Ahmad) for their feedback until a clear consensus on themes and patterns in the data emerged.

Following the development of the empirical model, we conducted a quality check of our categorizations and the themes we observed from the data by inspecting couple feedback data on the intervention. The purpose of the quality check was to ensure that the model appeared to be capturing what was most salient to the couples themselves, and accordingly, we would have an additional form of validation of the empirical model before synthesizing the models. Although this process of checking for quality is not part of the traditional task analysis method during the discovery phase of analysis, it was undertaken in the present study because it did not include the validation phase of task analysis where the model is tested with an independent data set Thus, the extra step included as part of the discovery phase served as a type of validation-check of our modeling. For every couple in the sample including both successful and unsuccessful cases, we scanned the post-treatment interviews and a treatment satisfaction survey created for Couplelinks (completed at post-treatment). The satisfaction survey looked at overall evaluation of the program. Participants provided feedback comments and 5-point Likert scale on which participants rated each item from ‘strongly disagree’ to ‘strongly agree.’ The quality check did not serve the purpose of modifying our analysis, but rather helped us to consider whether our themes were closely aligned to what the couple themselves were reporting and to reduce researcher bias when interpreting the results.

Step six: Rational-Empirical Synthesis. In the final step of the discovery phase, the rational and empirical models were compared with one another. The synthesized model integrated what was hypothesized and expected by the researchers within the rational model, and what was observed by the researchers within the empirical model. An overarching model of couple change was generated. In a classic task analysis, the rational-empirical model would be used within the next validation phase of hypothesis testing using quantitative analyses, and eventually to show causal determinations of change. We stopped at this point, as quantitative validation of the model is not our research aim, but nevertheless, the final, synthesized model represented the amalgamation of the process-oriented analyses which shows patterns of couple response within the intervention.

**Successful and Unsuccessful Case Selection.** To discriminate between successful versus unsuccessful couples and select the six prototypic cases (three couples in each group) for the task analysis, we used a pool of 31 couples participating in the treatment arm of the Couplelinks RCT. Seventy-five eligible couples participated in the RCT; following attrition, however, 31 couples remained in the treatment group (while 36 couples remained in the waitlist group). Three cases per group (successful and unsuccessful) is the suggested sub-sample for task analyses to pinpoint the most representative cases for deep investigation (Pascual-Leone et al., 2009). Three couples who were successful in the intervention and three couples who were not successful, as operationalized by 'good' or 'poor' relationship adjustment across time on the R-DAS, were selected for the task analysis (n=6). Table 1 shows demographic information for the six selected cases. Table 2 shows this final sample by case number identifier with individual, baseline R-DAS scores.

A task analysis determination of successful and unsuccessful cases begins by identifying cases based on expert or trained observers' perspectives and decisions. Chosen experts are generally involved clinically in the intervention (e.g., clinician, clinical judge, an expert in the therapeutic orientation delivered) (Makinen and Johnson, 2006; Woldarsky-Meneses, 2006). In addition to clinical judgements, selection of cases may also involve using the outcome measures to assist with differentiating cases of a resolved or unresolved, or change or no change status (Woldarsky-Meneses, 2006). In this study, we used this combination of tracking change over time using a select measure that was judged to be important following the RCT findings, in conjunction with clinical impressions of Couplelinks' facilitators in a triangulated fashion (see Triangulation section).

Participants in all conditions of the trial completed a battery of outcome measures at 3 time points: (1) baseline, (2) post-treatment, and (3) 3 months following completion of the post-treatment measures. We used the Revised Dyadic Adjustment Scale (R-DAS) outcome measure (Crane et al., 2000; Busby et al., 1995), as this was a primary outcome of the RCT, and no effect was seen on the R-DAS using the aggregate data of the RCT following statistical analysis (Fergus et al., 2021).

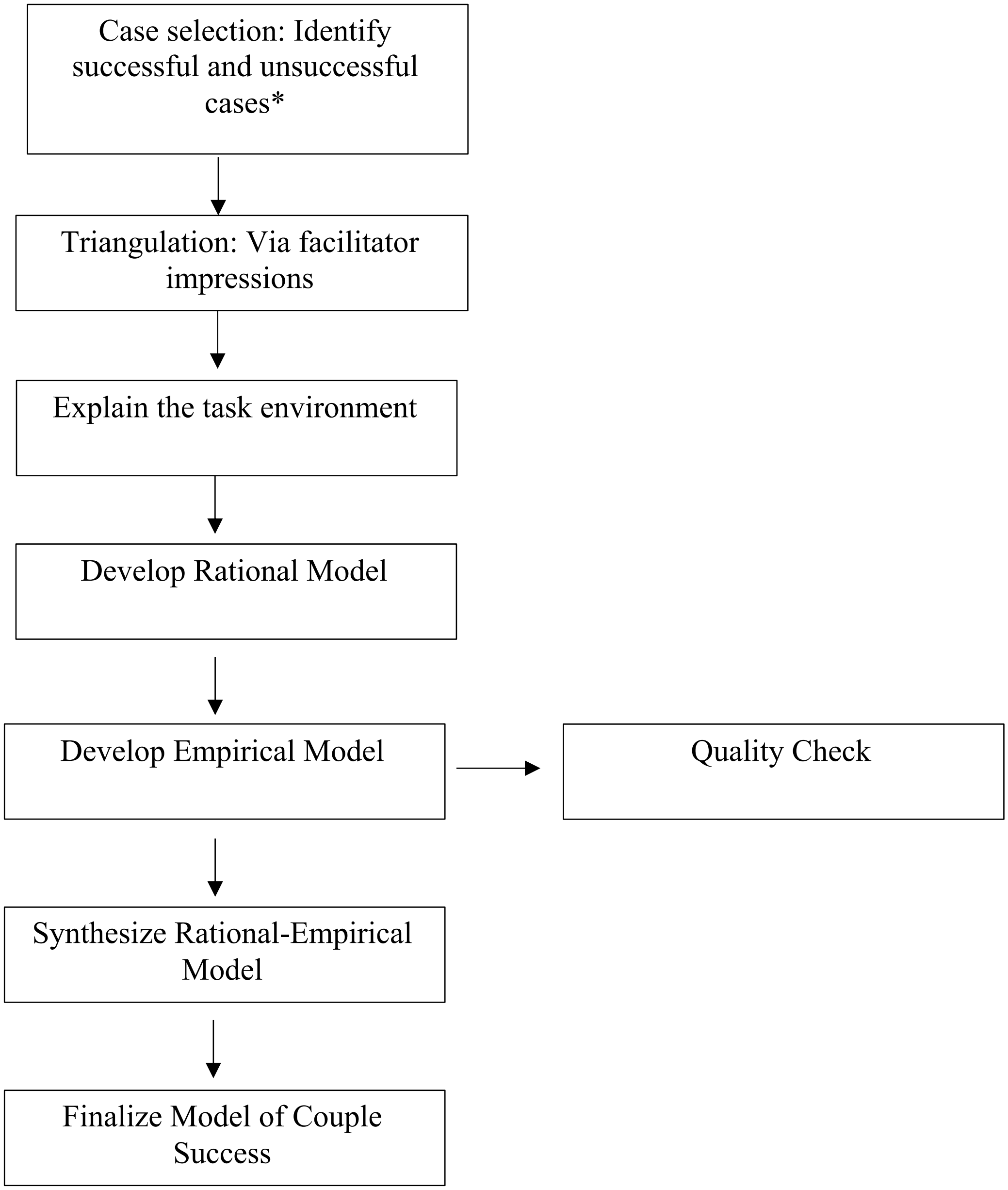
In order to classify and select three contrasting cases for each 'good' and 'poor' group, the R-DAS scores for each individual and each couple unit were plotted from pre to post intervention using simple line graphs. The successful couples' pre and post treatment scores on the R-DAS indicated positive change in their self-reported levels of relationship adjustment, while the unsuccessful couples showed a decrease on the R-DAS post-treatment. For couple change scores, "it is appropriate to average the individual scores to determine a couple score" (Crane et al., 2000, pg.58); thus, we calculated this single change score from pre to post intervention per couple. In addition, we looked at each individual's change score over time using plotted line graphs. Moreover, both individuals within the couple had to show change in the same direction for the couple to be selected for analysis. Couples with the highest change scores were selected as successful cases, and couples who worsened were selected as unsuccessful cases. Individual couples scores were similar, save for one couple (107) within the successful group. This specific couple is discussed within the Results section as to why they experienced positive change. Figure 2 shows the change in relationship adjustment over time for the six selected dyads from baseline (T0) to (T1) post-treatment. Figure 3 shows the change in relationship adjustment over time for the 12 individuals (male and female participants) from baseline (T0) to (T1) post-treatment.

**Triangulation**. The purpose of including subjective impressions in the selection method was to increase the confidence of the case selection. Clinicians who served as facilitators for the selected couples were contacted to obtain their impression of whether they thought their couples would have or not have shown improvement in relationship adjustment following their participation in the program. By engaging the original facilitators in providing their clinical impressions of each couple, we gained additional, subjective data that the objective graphs alone could not provide by simple visualization. All facilitators were blinded to the direction of the relationship adjustment change according to the objective, R-DAS.

Three of five facilitators from the original RCT were identified as having guided the six selected couples through the program (two couples per clinician). The facilitators for this sample included a social worker and two clinical psychologists all of whom are experienced clinicians with couples and psycho-oncology. Considering that the Couplelinks trial took place from November 2010-June 2015, it was important to provide a memory prompt to the facilitators to aid them with remembering their specific couples. Toward this end we provided them with de-identified Dialogue Room correspondence textual data, and the module feedback that each participant provided following their completion of each module. Facilitators were asked to provide their impression of whether, based on their recollection of the couple in question, they thought the couple would have demonstrated improvement on the R-DAS or not. We then held a consensus conversation with each facilitator to ensure we understood their impressions and to allow them to explain their rationale for their impression and categorization of the couple into the improved or not improved group.

Figure 1.

*Task analysis steps*



*As demonstrated via positive change scores on the R-DAS

Table 1.

*Participant demographic information: From the six couples in the task analysis sample (N=12)*

*Demographic Information*

| **Variable** | **Female (Mean)** | **Male (Mean)** |
|---|---|---|
| Age | 36.83 | 41.83 |
| Age at Diagnosis | 35.33 | |
| Length of Relationship | 12.67 | |
| Number of Children | 1.33 | |

| **Variable** | **Female (N)** | **Male (N)** |
|---|---|---|
| Location | | |
| British Columbia | 2 | |
| Nova Scotia | 1 | |
| Ontario | 3 | |
| Ethnic Background | | |
| Anglo-Saxon | 2 | 6 |
| Caucasian | 2 | 0 |
| French-Canadian | 1 | 0 |
| Métis | 1 | 0 |
| Educational Level | | |
| College Program | 4 | 3 |
| High School | 0 | 1 |
| University Degree | 2 | 2 |
| Employment Status | | |
| Employed | 6 | 6 |
| Unemployed | 0 | 0 |
| Student | 0 | 0 |
| Marital Status | | |
| Married | 5 | |
| Common Law | 1 | |
| Living Situation | | |
| With partner | 3 | |
| With partner and child(ren) | 2 | |
| With partner and parent | 1 | |

**Illness Variables**

| | | |
|---|---|---|
| Cancer Stage | | |
| Stage 1 | 3 | |
| Stage 2 | 1 | |
| Stage 3 | 1 | |
| Illness Point | | |

| | |
|---|---|
| Recently diagnosed | 0 |
| Receiving active treatment | 3 |
| Receiving follow-up care | 3 |
| Type of Surgery | |
| Single lumpectomy | 1 |
| Single mastectomy | 3 |
| Bilateral mastectomy | 2 |
| Reconstruction | 4 |
| Type of Therapy/Treatment | |
| Chemotherapy | 6 |
| Radiation | 4 |
| Hormonal | 4 |
| Herceptin | 2 |
| Other Treatments or Surgeries | |
| Hysterectomy | 1 |
| Prophylactic Hysterectomy | 1 |
| Oophorectomy | 1 |

Figure 2.

*Change in relationship adjustment over time for the six selected dyads from baseline (T0) to (T1) post-treatment*

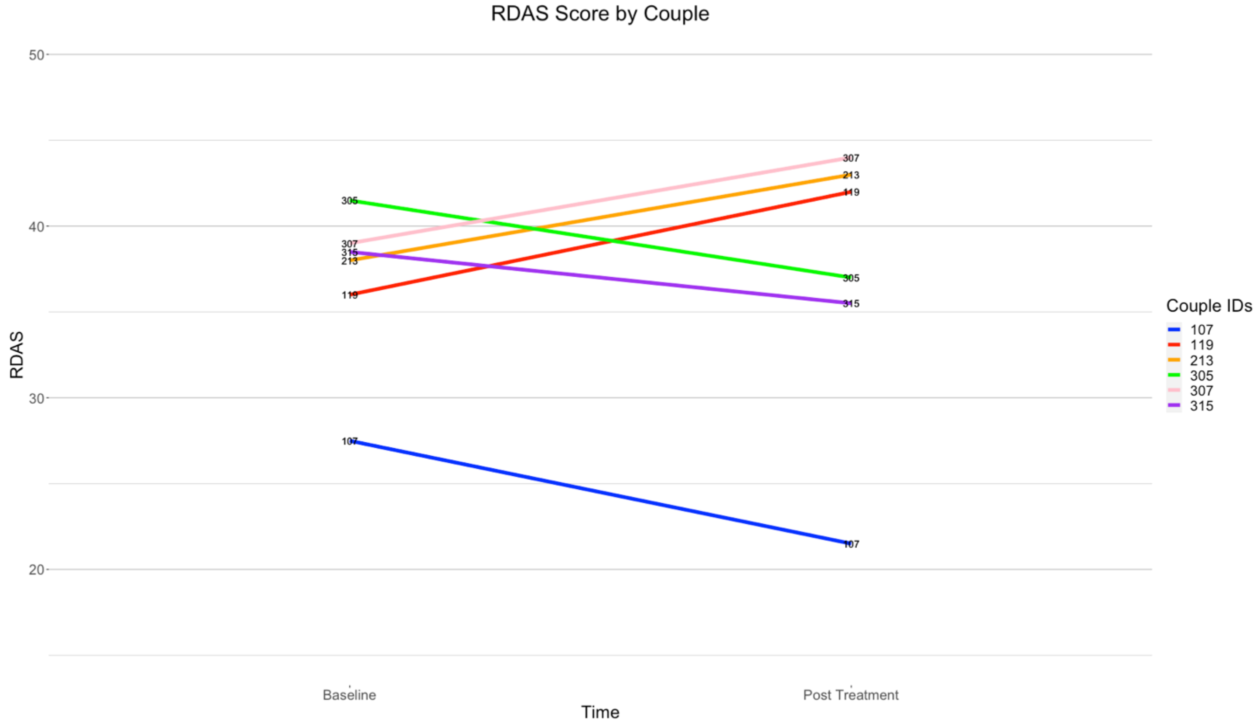


Figure 3.

*Change in relationship adjustment over time for the 12 individuals (male and female participants) from baseline (T0) to (T1) post-treatment*

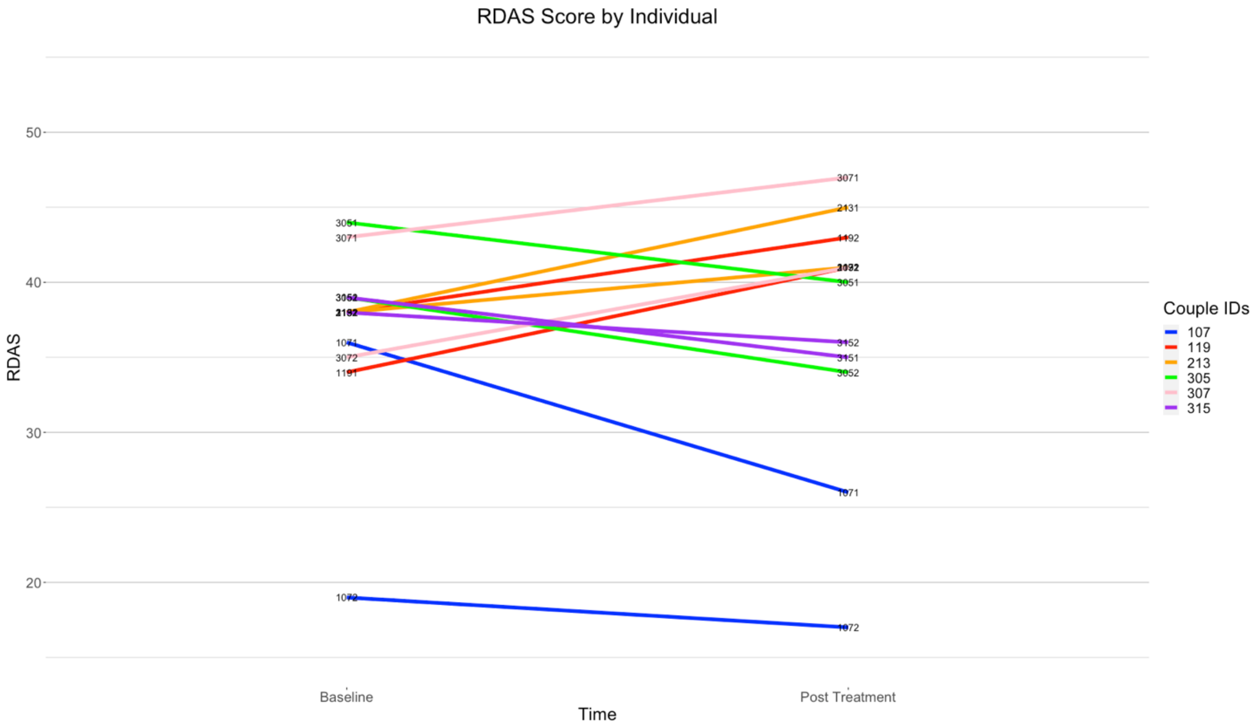


Table 2.

*Sample of Six Selected Cases (By Couple Code) with Participant Baseline R-DAS Scores**

| **Successful Cases** | **Baseline R-DAS** | | **Unsuccessful Cases** | **Baseline R-DAS** | |
|---|---|---|---|---|---|
| | Female | Male | | Female | Male |
| Couple 119 | 34 | 38 | Couple 107 | 36 | 19 |
| Couple 213 | 38 | 38 | Couple 305 | 44 | 39 |
| Couple 307 | 43 | 35 | Couple 315 | 39 | 38 |

*Note: Scores of 47 and below indicate relationship distress on the R-DAS (Crane et al., 2000)

]

# Results

## Rational Model of Dyadic Success within Couplelinks

The rational model of obtaining benefit from participating in the Couplelinks intervention is based on the experts' expectation (grounded in their knowledge and clinical experience) of couple change processes. In this study, two clinical psychologists responsible for the development and delivery of Couplelinks, each of whom possessed research and clinical experience in psychosocial oncology and therapeutic treatment of couples, consulted with the primary author.  The rational model, presented as a hypothetical map of mechanisms that led to successful change among YWBC couple participants, is shown in Figure 4. This schematization was intended to capture what the research team believed would be the critical 'unfolding' of internal and external events leading towards dyadic change. The rational model contains five categories described below.

### *1.Motivational Alignment*

It is expected that both individuals in the couple dyad would display a similar level of openness to, and motivation for the intervention and the modules, as well as receptivity to the facilitator's input. The questions that the researchers held in mind about the couple were:
1) Is there a sense of congruency between partners in the way that they approach the intervention? i.e., both are relatively equally interested and motivated to participate; 2) How are they relating to the intervention - is it a perfunctory type of engagement or is the couple more fully 'immersed' within it? The research team also deemed that both members of the couple would feel intrinsically motivated to engage with the intervention, as opposed to having an extrinsic reason for participation (e.g., 'a member of my healthcare team thought this would be good for me').

### *2. Other-Awareness*

The research team anticipated that members of the couple would show interest in their partner's experiences. Specific to the cancer-focused intervention, it was thought that partners would show a level of curiosity about the other's cancer journey, and notice how their partner was feeling regarding their relationship functioning and their experience of the illness regardless of their 'patient' and 'caregiver' roles.

### *3.Emotional Contact*

The research team hypothesized that each partner would demonstrate a positive emotional reaction, such as love or adoration or warmth or intimacy, toward their partner as they moved through the intervention together. Couplelinks, as a relationship enhancement intervention, was not intended to provoke in-depth processing or problem-solving work within the relationship as would occur in couple therapy. However, it was anticipated that there would be presence of vulnerable emotions that would arise for successful couples whereas unsuccessful couples would avoid or deflect them. Given the emotionally charged context of cancer, we felt that there would be the presence of emotional 'valence' that would arise between partners.

### *4.New Learning*

With this category, it was felt that there would be evidence of novelty, thinking, and learning among the successful couples, whereas there would be a lack of newness among unsuccessful couples. In other words, successful couples would show relative profundity of new insights or new skills whether they be small or large, and this evidence would be lacking and hard to see among unsuccessful cases.

### *5.Relational Integration of the Breast Cancer Experience*

It was anticipated that successful couples would reflect on their shared experience of the female partner's BC diagnosis and come away with a better understanding of how BC has impacted their relationship. Given that young couples' relationship adjustment tends to suffer as a consequence of the illness and relationship distress tends to increase, it is expected that the couples would need to increase their awareness of this risk factor. After partaking in Couplelinks together, the couples would emerge with a better understanding of how BC has impacted their own relationship, and associated knowledge and methods of relationship enhancement.

## Empirical Model of Dyadic Success within Couplelinks

The empirical model of dyadic adjustment success shows change mechanisms that were gleaned from the Couplelinks dataset. The data sources that were used to develop a thematic structure consisted of the module (or DLM) content, DLM feedback, and Dialogue Room (DR) correspondence between the facilitator and couple. The empirical observation of the three successful couples and three unsuccessful couples led to the discovery of patterned differences between the two groups. These differentiating themes resulted in three main categories: (1) Embracing the Program, (2) Mutual Agency, and (3) Tangible Dyadic Changes. The empirical model describes the actual events and processes that we observed from the couples themselves via their text-based entries and their written communications with their assigned facilitator. The empirical model is presented in Figure 5. The empirical model with summary definitions is presented in Figure 6. When individual participants are quoted, we indicate who is speaking with the couple code and the participant's gender (e.g., Couple119F refers to the female participant's voice in dyad #119). Table 3 shows participant representation across all categories where the pattern of distinction between the two groups is visible.

### *1.Embracing the Program*

This category encompasses features about the couple unit, specifically how partners interact with the intervention. The themes subsumed under this category show two things: (1) characteristics of the successful and unsuccessful couples as they interact with each other, and (2) as they interact with the Couplelinks intervention. What is detailed in this empirical category is how the couples interact with and engage with the intervention at different points in time. We saw different degrees of couples 'making space' for the intervention which contributed to relative success or not.

**1a. Running start.** What was observed among the successful couples group was an evident, initial enthusiasm 'straight out of the gate' from the beginning. This subcategory refers to how the couples position themselves within the first modules, specifically Modules 1 and 2. These couples showed a readiness to get started and that they were proactively already considering how to best use the intervention to enhance their relationship. We likened this couple characteristic to 'stretching'/warming up before an athletic endeavour, where the individual is about to engage in the energy exertion and are actively preparing their body for the effort. For example, one male partner described in Module 1, "I see avenues that will open up as we go" (119M) referring to ways in which he sees how he and his partner might be able to learn from the intervention. Similarly, 119F also states in reference to Module 1 "I'm looking for our strengths together. I was able to see how much we support each other as a couple, not one of us more than the other." Her language of "I'm looking" shows her 'ready-to-go' stance and action-oriented framework with which she begins the program. Two of three of the successful couples were united in their 'running start' position, whereas with the third successful couple, only the female partner demonstrated this stance while her partner appeared to take a more passive, 'laissez-faire' attitude at the beginning of the intervention (Couple 213). For example, in the first two modules, this partner responded consistently in the feedback segment that he was not connecting with the intervention. Specifically, following Module 2 (Understanding Your Partner's Inner World), where partners are asked questions about the other partner's perspective on matters ranging from trivial to more serious topics, he stated "some of the questions seemed silly." (213M).

In contrast, all of the unsuccessful pairs were not as ready from the 'get go.' For Couple 305, for instance, the facilitator was tasked with ensuring they partook in the modules, rather than the couple independently completing them. We can see in the DR that their facilitator was checking in from the start, and this pattern of incompletion and the facilitator consistently sending reminders continued throughout the intervention. For example, the facilitator stated: "I just wanted to check in with the two of you. I noticed that you have not yet started Module 1, and wanted to make sure that you didn't have any difficulty logging in? Please let me know where you are at with this when you have a chance."

**1b. High Utilization and Involvement.** This category refers to the strong commitment that successful couples had to their uptake and participation in the intervention. An indication that the couple was involved with the intervention was that they were attentive to the content of the modules. For example, in Module 1, each individual was asked to list positive qualities of their partner, their general couple strengths, and to identify couple strengths important to coping with cancer. The male partner in Couple 307 demonstrated his interest in engaging in the intervention when he stated within the module feedback section, "We are on the same page on many issues but we still have a lot to work on to strengthen our relationship" (307M). By the same token, we can see the female partner in the couple interacting well with the intervention content, shown by her depth of thought and personal reflection here. She stated:

> I've become a bit boring. That the things [partner’s name] values in me are important as a person and as a couple, but that I've lost my enthusiasm in a lot of what I do ... and it has spilled over to our relationship and we're not as fun anymore.

Although she reflects on a ‘negative’ element of their relationship, her ability to absorb the instructions of the intervention and to provide a response that is thoughtful, personally meaningful, and suggestive of impetus for change are reflective of the degree to which the couple engaged with the module. We also found evidence of high involvement when successful couples remarked that a module was “enlightening” (119M), “it really made me think” (119F), or “it was good to think back together and see what each person thought of” (213M) demonstrating active participation through completion of a given exercise.

Within the DR correspondence for Couple 307, their facilitator commented on the couple’s level of engagement with the program, specifically how the couple intended to use the intervention towards their specific goal(s). Following completion of Module 1, the facilitator stated, “I can hear your equal and shared motivation to reconnect with each other, and as you said, (female name), ‘we would love to get the closeness back and become stronger together’” (Facilitator for Couple 307). For the unsuccessful couples, however, they did not utilize the modules to the same, deeper extent as the successful couples. For instance, for the male participant in Couple 107, he appears to be lacking engagement following Module 2, where participants are asked about their internalized representations of one another by sharing the other partner’s likes and dislikes (including in relation to the illness experience). When asked for his reflections on this exercise, he simply stated, “it like a quiz about our life together (107M).” Here, we can see that although he was participating, he was not particularly drawn to or interacted with the module in depth.

**1c. Differentiated Response Style**. This category refers to the manner of articulation we observed among successful couples compared to the unsuccessful couples. Generally, those in the successful group provided more detailed and thoughtful responses to the module prompts and feedback questions at the end of each module, whereas the unsuccessful group was more likely to provide sparse comments and low-level feedback. What we can glean from these styles of responding are different levels of processing of the module content. Cognitively and emotionally, those couples who narrated in detail were appeared to be processing their experience with the module more deeply. For example, we saw a rich description of a 'turning toward' event – a task that was part of Module 3— which showed evidence of a female participant's in-depth thoughtfulness towards her partner. We really see her efforts here:

> [Partner's name] has said that he feels like he is alone in the field, and has no one working with him to encourage him. I knew that he could reach his [weekly sales] goal, and he is always encouraging me in so many ways, I wanted to do the same for him. We both can share in each others' success, and we are a team (119F).

She goes on to state in the same module: "I wrote an encouraging note to tuck inside his lunch bag, he has a weekly sales goal he is trying to reach and I wanted to send some positive thoughts with him" (119F).

When we compare this description to one participant's response style within Module 3 who was part of the unsuccessful couples' group, we can see a stark contrast with the style of text, where the response was featureless and devoid of detail. This female participant said: "He asked for breakfast, and I know he likes eggs, so I made it for him" as her example of a 'turning toward' event (107F). Essentially, we saw this pattern of low-level detail narrative in the unsuccessful couples. They provided one-word answers such as "yes" or "no" when asked if they liked or learned something from an exercise and gave more vague answers such as "It was nice to have a massage, I've never had one before" (305M, Module 5- Sensate Focus). What was also typically seen among unsuccessful couples was a lack of explanation for their disinterest. For instance, both the male and female partner in couple 315 stated they did not learn anything new after completing Module 5. The female partner said "not really" and the male partner said "I don't think so." From the perspective of the researcher, what is left after these types of undetailed comments is a desire for follow-up and to understand why the couple did not learn anything new and to learn more about their reaction.

### *2. Mutual Agency*

Whereas the previous category represented a descriptive look at how couples interacted with the intervention, this category describes factors intrinsic to the couple that contributed to positive change. Couples who demonstrated certain relationship behaviours and deeper awareness were propelled onto a path of greater success and adjustment in the intervention.

**2a. Diving into Understanding of Self and Other.** This category refers to the participant's ability to demonstrate thoughtfulness and awareness of the other. A step further than just simply noticing, the individual can articulate what their partner may be feeling, and in turn, may try to reflect on or modify their own behaviour to suit their partner. The individual indicated that they were working to learn more about their partner and to integrate new information about themselves, their partner, and/or their relationship, towards an end goal of improving their relationship. For example, following Module 3 (entailing creating connections via tracking relationship behaviours) we saw the female partner in one successful couple show her understanding of how her relationship is affected, namely how her partner suffered, when she was not present during their exchanges:

> Sometimes I don't pay attention to what he is trying to say to me, or only listen to some of it. I need to try and be more present when he has something to say, and not read more into what is being said. If I don't understand what he is saying, then I need to ask, and not jump to conclusions (119F).

We were also able to see how two partners interpreted the potential for new information after partaking in Module 3, as evidence of their level of openness to learning about the other and their relationship strengths. One female participant stated, "I learned that there are little things that may go unnoticed day-to-day but because I had to track them for a week, I payed more attention to how we acted toward each other (213F)." Within the same module feedback response, the male partner stated: "I learned there are little things I do that make my wife happy (213M)." Although the male partner was sparse and vague in his response (as was characteristic of this participant throughout the intervention), both members of the couple articulated evidence of 'wheels turning' and becoming more attuned to one another. This demonstration of 'diving into understanding' could be contrasted with an unsuccessful couple's manner of responding to their partner. The unsuccessful group articulated that they had little room to grow in their relationship (in that they already possessed a high degree of mutual understanding) and thus did not necessarily need to delve deeper into their relationship. For instance, one participant from the unsuccessful group said after Module 2, "It's fun to see how much you know about your partner (305M)." Here, we saw that although the participant reflected favourably on the module, there was a lightness to his response; deeper processing of this insight was potentially not needed. The female partner in this couple also expressed throughout the intervention that she felt already aware of her partner and their relationship functioning, and the nuanced behaviours between them. However, such consideration of her partner was not so much a result of participating in the intervention; rather she attributed this quality to her pre-intervention way of relating to him. In sum, the distinction between the poor and good outcome groups was a budding awareness versus a lack of it and/or that the awareness was already present.

**2b. Within-Couple Alignment.** This category exhibits the varied ways in which the successful couples had similar views throughout the intervention. For some couples, they showed comradery and similar likings and values. Couple 119 shared that they hoped they would buy a motorcycle, as “something we have been wanting since we got together” (Couple 119). This couple noticed their matched supportiveness to one another in what they felt was a meaningful part of their relationship. The female participant said: “In looking for our strengths together, I was able to see how much we support each other as a couple, not one of us more than the other” (119F). An example of a profound sense of shared coping amidst cancer was commented on by couple 307 after completing Module 4 (a creative expression exercise where couples metaphorically portray the impact of cancer on their relationship). The facilitator for this couple captures their alignment within the DR correspondence.

> The joint focus of this module highlighted how although cancer was “a boulder is something between us, as opposed to something that we climb over together”, your experience has been in many ways more similar than different. As [Female participant’s name] said, you share “many similar feelings” and your “frustrations and struggles are very similar both individually and together as a couple.” Underlying this “obstacle that keeps changing shape”, [Male participant’s name] also was reminded that you “do work well together and that we share similar concerns (Facilitator for Couple 307).”

On the other hand, Couple 213, a couple within the successful group, was an exception to the theme of alignment when it came to a sense of congruency with respect to the intervention.

Whereas the female partner appeared more engaged, verbalised more often and with greater depth, the male partner said little and was not necessarily learning from the intervention in the same obvious manner exemplified by his partner and the other successful couples. Nonetheless, it was noted by the research team and the couple's facilitator, that although the male partner was 'slower to warm' to the intervention, in the end, he appeared to demonstrate new learning and attention to his relationship in later modules. In earlier modules, he would state "I did not find this useful", yet it was also noted by his facilitator that the male partner was able to notice the couple strength in his partnership. We can see this here:

> [Male participant's name], you're a man of few words—but what you've said is truthful! Clearly there is much that sustains you as a couple. You're right that often couples don't take the time to remember to tell each other what they appreciate about them- not a bad idea to make little affirmations a part of a 'date night' or something like that (Facilitator for Couple 213).

Overall, 'Within-Couple Alignment' is characterized by when the couple showed similarity in different areas, for instance how they felt about the intervention, their shared reality, and how they worked and coped together. Interestingly, with the unsuccessful group, our expectation was that those couples would have mismatched experiences, yet they were also aligned in their experiences of the intervention, albeit from more of an unenthused place. Their alignment was contained to feeling similarly about the intervention, namely a united resistance to taking up its principles. For instance, following Module 4 (the creative expression exercise), one female participant stated "I don't know if it was beneficial, just nice to be creative together" (107F) and her partner echoed the same sentiment, which is that they were not connecting to the module (and the intervention as whole).

**2c. Valuing My Partner.** Successful couples expressed positive feelings towards one another even when not prompted by the intervention to do so. Asking partners to speak highly about their partner was an explicit prompt of Module 1— "Celebrating our Strengths" — however, what was unique among the successful couples' group was that they tended to display spontaneous expressions of prizing the other in modules that didn't explicitly guide participants in that direction. For example, we can see one female participant noticing her partner's gentleness and appreciating him for it when she was asked to recall the experience of the Sensate Focus exercise in Module 5, where partners are asked to engage in non-sexual touching to facilitate connection and intimacy, not necessarily sexual activity:

> I knew that he was getting aroused, I haven't been naked around him much lately. He saw that I needed to ease into it, and he was gentle and slow, it just made me feel closer because he really understood what I needed at that time, and I was able to relax and enjoy the moment. It is these times, that I just want to lay in bed together and cuddle and chat (119F).

The male partner returned these affections spontaneously by stating "I love [partner's name] to infinity and beyond" (119M) following this same module. Similarly, another male participant expressed the appreciation of his partner surprising him by making a reservation at their favourite restaurant. He stated: "This was a VERY nice surprise and was GREATLY appreciated!" (307M). His enthusiasm was conveyed with his capitalization and punctuation, and we were able to see how he valued being surprised, and his partner enacting this surprise for him.

In direct contrast to the successful couples, we observed a dearth of unprompted valuing or celebrating the other in the unsuccessful group. Given that Module 1 was designed for partners to state the positive qualities they see in their partners, it was expected that we would see this occurring in this specific module across couples irrespective of outcome. What is different about the successful couples was the ability to integrate this module's lesson and to apply it in later stages when it was not asked of them. Thus, the ability to notice and to express revere about one's partner and/or his or her behaviours that benefitted the relationship is an observable characteristic that was bound to the successful group.

### *3. Tangible Dyadic Changes*

This category represents concrete benefits that the successful couples gained from the intervention. The essence of this category is novelty. The couple has gained something new, whether a skill, reflection, or understanding, as a result of Couplelinks.

**3a. Adopting New Relationship Skills.** This category refers to behavioural changes that are tried out or seen among the successful couple group. There was a clear indication that the couple is enacting a relationship-enhancing skill vis a vis their awareness of their personal style of interaction. The importance of Module 3 ("Creating Connection") stood out with respect to shaping this category. In this module, partners were tasked with observing their interactions and independently tracking their 'turning towards and turning away' behaviours (Gottman, 1991) over the course of the week. For instance, we can see the insight that one male partner had when he reflected on what is a turning toward versus turning away behaviour, and integrating his new knowledge into future actions.

> At first I was looking for extra-ordinary examples, but then realized that there were simple, every day moments that were examples. While, I only provided one occurrence of putting cream on [Female participant's] feet/legs, I try to do it every day or at least after every time she takes a bath. (307M)

The facilitators who were assigned to the successful couples appeared to echo what was being conveyed by participants within the module content, namely that couples were engaged with Module 3 and trying a new skill. With respect to Couple 213, the facilitator stated in the DR how the couple showed depth in their experience, and points out their budding skill of noticing and translating their awareness of the other's needs into tangible behaviours, such as "bringing home dinner".

> It's amazing how many 'little things' like those you've described go unnoticed by either the one doing them or the one receiving them. What we know of successful marriages is that the number of positive interactions far outnumbers the number of negative ones. It strikes me that you both naturally do a number of small things that mean a lot when you take the time to reflect on them—like bringing home dinner, cuddling, massaging [female name] head (and what hair remains ☺) (Facilitator for Couple 213).

In addition, participants were inclined to share their enthusiasm regarding Module 3, both in terms of satisfaction and capacity for learning. For example, one participant stated "I realized that there were very simple, daily examples of "Turning-toward" moments. I also realized that there are probably more "Turning-away or against" examples that I did not realize I probably committed?" (307M). As another example, when conveying her appreciation of the module, one female partner talked about the benefit she derived from Module 3: "I found it beneficial because it really made me more aware of our behaviours, and if there are any triggers to the way we act towards each other" (119F).

A prominent contrast observed between the successful and unsuccessful couples was that those in the unsuccessful group were reporting little room for growth or awareness-building. These couples tended to state that they already were aware of their relationship-enhancing versus relationship-eroding behaviours, and thus some of the modules, with the exception of Module 3, did not serve them. The unsuccessful couples did not report that they valued the intervention as much as the successful couples. Following Module 6, one participant said: “Other than a history review, I saw no benefit” (107M). This was the case across unsuccessful couples. Interestingly, the facilitators also noticed that the unsuccessful couples did not require relationship-enhancement tools following cancer due to the strength of their relationship. For instance, one facilitator commented, “the strength of the intimacy and connection of your relationship has sustained itself after diagnosis” (Facilitator for Couple 305). Essentially, those in the unsuccessful group communicated in their feedback that they already had pre-existing positive behaviours, thus building new awareness to lead to new skills, was not needed.

However, with respect to Module 3, we saw a deviation in this pattern of a lack of reported benefit. For one unsuccessful couple, they were ‘pulled’ towards Module 3 more than the others. The female participant remarked: “It is nice to actually point out the good that is happening, even the small things” (107F), and the male partner in this same couple said “it would be good to put this into practice” (107M). What we can see here is not necessarily the same level of high enthusiasm for Module 3 that the successful couples had, yet this particular unsuccessful couple was at least able to assess and acknowledge the potential importance of Module 3 and its potential benefit, even if they did not feel they needed it or were indifferent to including foundational awareness skills within their relationship-behaviour repertoire.

**3b. Explicit New Learning.** This category explicated the tangible output of successful couples. When the couples demonstrated new learning, individually or even more powerfully as a unit, we were able to see a ‘newness’ that was not present before. The indication of novelty occurred in their feedback, in the module content, tone, reflection and awareness, and positive behaviours towards one another. These skills were deemed to change relationship functioning in the positive direction, whereas an absence of new learning may indicate stagnation. Both individuals in Couple 119 (a successful dyad), towards the end of the intervention, showed that they agree on their personal reflections about their coupledom, in particular how they have coped with adversity. In Module 6, participants created a relationship timeline/story to situate the illness in their larger relationship history and to consider new directions for the future. Conveying a new relationship identity between them was a novel process that occurred for this couple. The male partner stated (119M):

> When [partner name] and I got together we were just about at rock bottom. We have rised through the ashes like a phoenix to owning three vehicles, camper, house. Our kids are doing well. So we are grateful for all the ups and downs because we have survived and our love has only grown stronger.

He goes on to reflect on this same principle which he felt will be a source of 'couple strength' in the future. He states, "…[We] are not perfect but we will survive a bump in the road is only a speed bump and will not slow us down. Good or bad things that have happened have only made me love [female name] more." (119M). Importantly, the female partner echoed her partner's sentiments when she stated, "It was nice to reflect on some of those early years, we realize we have come a long way from where we started, in our personal and professional lives" (119F). We also saw evidence of new learning when one partner had a realization about their own role within the relationship. For example, one participant stated, "That my own resentment gets in the way of our relationship a lot. I knew that already, but [the module] illuminated it even more. That I am putting up barriers and turning away more rather than turning towards" (309F).

In contrast, the unsuccessful couple group in response to Module 6 specifically and the exercises in general, did not show this type of narration or evidence of new thought. For example, by stating “nothing new here” (315M) or “It was nice to reflect on our history together” but with no mention of having deepened understanding of the other or the relationship (107F). In general, these were the types of mild, featureless, and inactive examples that emerged with the unsuccessful couples.

Interestingly, with the unsuccessful group, it is not necessarily that they only showed a lack of new learning, but that the intervention was rather affirming for them (i.e., showed them what they already knew about their relationship), and thus there was less room for growth or improvement. For instance, Couple 315 seemed to consistently remark that they already had communication skillsets and knew themselves and each other well, thus the modules either affirmed or bolstered this part of their couple unit. After completing Module 6, the male participant stated, “It was a nice reinforcement of our assumption that we're awesome.” (315M). It was common to see the facilitators stating that the modules were reinforcing for the couple, rather than revealing something novel and/or important for the couple. The facilitator for couple 305 wrote to this couple in the DR that what they garnered from Module 2 was an opportunity to review what they already knew, like “the two of you are already aware of the each other’s finer qualities as well as the strengths of your relationship” and “it seems as though there were no real surprises” (Facilitator for Couple 305). Another facilitator with a different couple pointed out that the intervention helped them to recall what was already present between them when it came to defining their cancer journey. This facilitator stated:

> What’s nice about your responses too is that you express openness and caring, and recognize that you’ve both been there for each other and gone through the cancer

> experience together. It feels good to remember that you are ‘in sync’ in many ways (Facilitator for Couple 107).

In sum, the new learning theme is defined by clear novelty that emerged for the couple because of the intervention to enhance their relationship. By way of comparison, for Couple 315 in the unsuccessful group, the facilitator commented on their relatively smaller room for growth:

> Your feedback that the ‘intentional dialogue’ felt overly structured and a bit awkward is completely understandable, and though you don’t feel like it illuminated anything in particular about your relationship, it sounds like it may have a tiny space in your 'communication toolbox’ (Facilitator for Couple 315).

## Synthesized (Rational and Empirical) Model of Dyadic Success within Couplelinks

The synthesized model presented in Figure 7 represents an integration of the rational and empirical models. The rational model is a hypothetical step-by-step series of factors that is driven by scientist-practitioner expertise in regard to the phenomenon under study. It is a postulated model, whereas the empirical model is data-driven and observable. In our synthesized model, which shows the amalgamation of process-oriented patterns of change, we can see that the rational model is linear in fashion. We thought one change mechanism would lead to another i.e., presence of one element must precede another. Yet, what was found in the empirical model was a more complex relationship towards change, wherein different components for each couple do not necessarily build on one another but rather we saw a pool of mechanisms that contribute to improved relational adjustment. Nonetheless, elements of both the rational and empirical models should be retained in the production of a fulsome theory of change (Greenberg et al., 2007). The synthesized model offers this. In this model, we did not retain the theme of “emotional contact” as it was not observed during the empirical modeling phase of analysis.

Participants in the successful group did not necessarily show positive emotion such as love or adoration, rather they displayed spontaneous prizing and/or valuing of their partner (as was captured in the ‘Valuing My Partner’ theme). The image shown in Figure 7 represents the integration of the hypothetical and the observable in a final model of dyadic success. Together, the synthesis is our model of benefit (as operationalized by improved relationship adjustment from pre to post-intervention) for the Couplelinks intervention.

Figure 4.

*Rational Model of Change among Successful Couples*

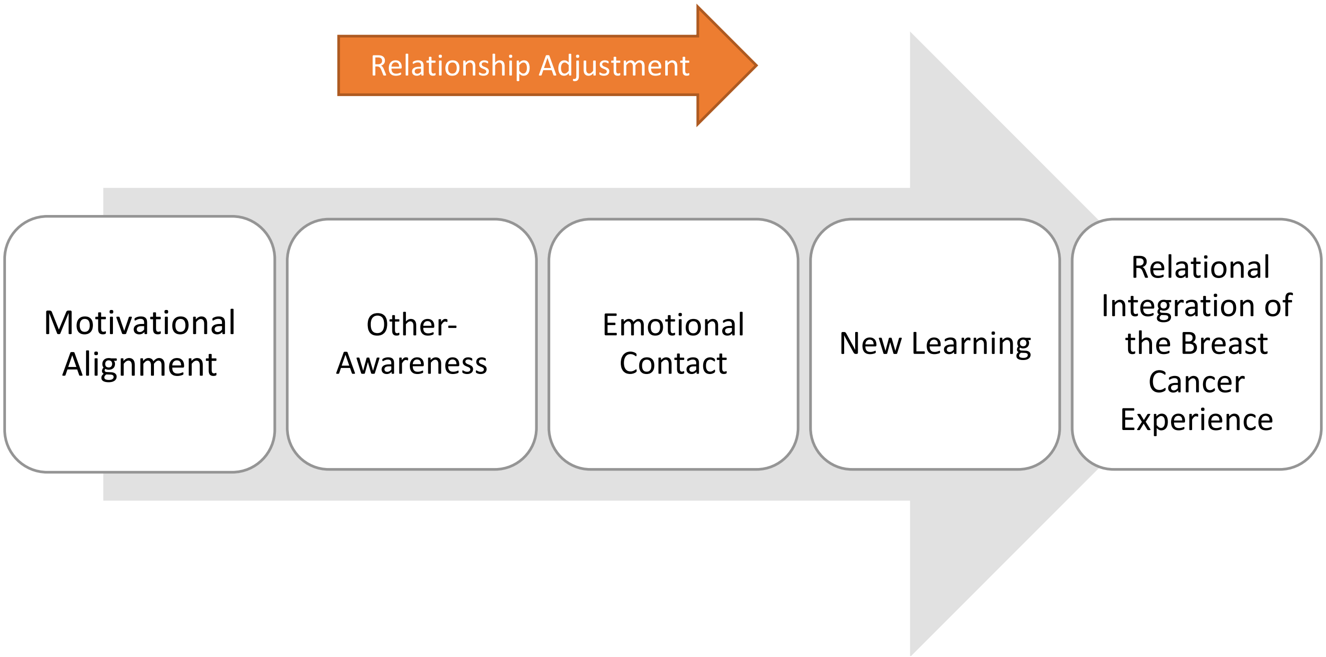


Figure 5.

*Empirical Model of Dyadic Success*

| **1. Embracing the Program** | **2. Mutual Agency** | **3. Tangible Dyadic Changes** |
|---|---|---|
| Running Start | Diving into Understanding of Self and Other | Adopting New Relationship Skills |
| High Utilization and Involvement | Within-Couple Alignment | Explicit New Learning |
| Differentiated Response Style | Valuing My Partner | |

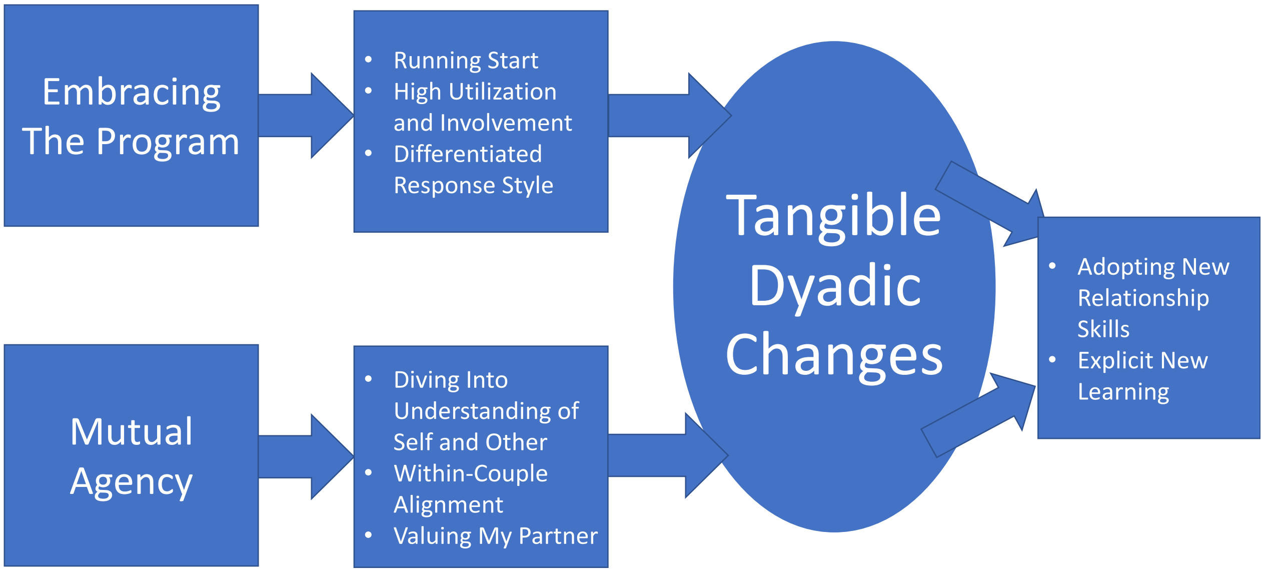


Figure 6.

*Empirical Model of Dyadic Success, with Subcategory Definitions*

| **1. Embracing the Program** | |
|---|---|
| **Subcategory** | **Definition** |
| 1a. Running Start | The couple expresses a high level of readiness and concurrent motivation to use the intervention to their benefit. They show evidence of thought of how they can apply the intervention to enhance their relationship. In essence, they show a level of readiness to commit to the program, early on in the program. |
| 1b. High Utilization and Involvement | The couple are high utilizers of the intervention. They demonstrate a connection, involvement, and attentiveness to the contents of the intervention.<br>Is the individual and/or couple ‘checked-in’ or ‘checked-out’? |
| 1c. Differentiated Response Style | The style of text-based narration throughout the intervention is detailed, individualized, open, and enthusiastic. The couple’s way of articulating their responses and feedback provides a sense of their connection to the intervention. |
| **2. Mutual Agency** | |
| **Subcategory** | **Definition** |
| 2a. Diving into Understanding of Self and Other | The couple shows a budding awareness of their coupledom. The couple shows preliminary development of attunement to their relationship and one another. A clear indication of this sub-category is when individual members show curiosity about their partner’s inner world and experiences. |
| 2b. Within-Couple Alignment | The couple shows similarity in different areas, for instance how they feel about the intervention, their shared perceptions, and how they work and cope together. |
| 2c. Valuing My Partner | The couple expresses positive feeling for their relationship and their partner. Notably, these expressions may be spontaneous (i.e.., not prompted) by the intervention. They |

| | |
|---|---|
| | communicate that they prize and value the other. |
| **3. Tangible Dyadic Changes** | |
| **Subcategory** | **Definition** |
| 3a. Adopting New Relationship Skills | The couple shows evidence that they are trying out and attempting to build new relationship-enhancement skills. Couples begin to enact what they have learned. Module 3 (Turning Towards and Away) stood out as an important module in terms of couples' practicing new strategies to integrate in their relationship unit. |
| 3b. Explicit New Learning | The couple show a turning point, novelty, and/or change within their relationship functioning that was not present before or at the beginning of the intervention.<br>With successful cases, change can look like a series of small changes or grand change(s). Additionally, the change in the couple is meaningful and purposeful. |

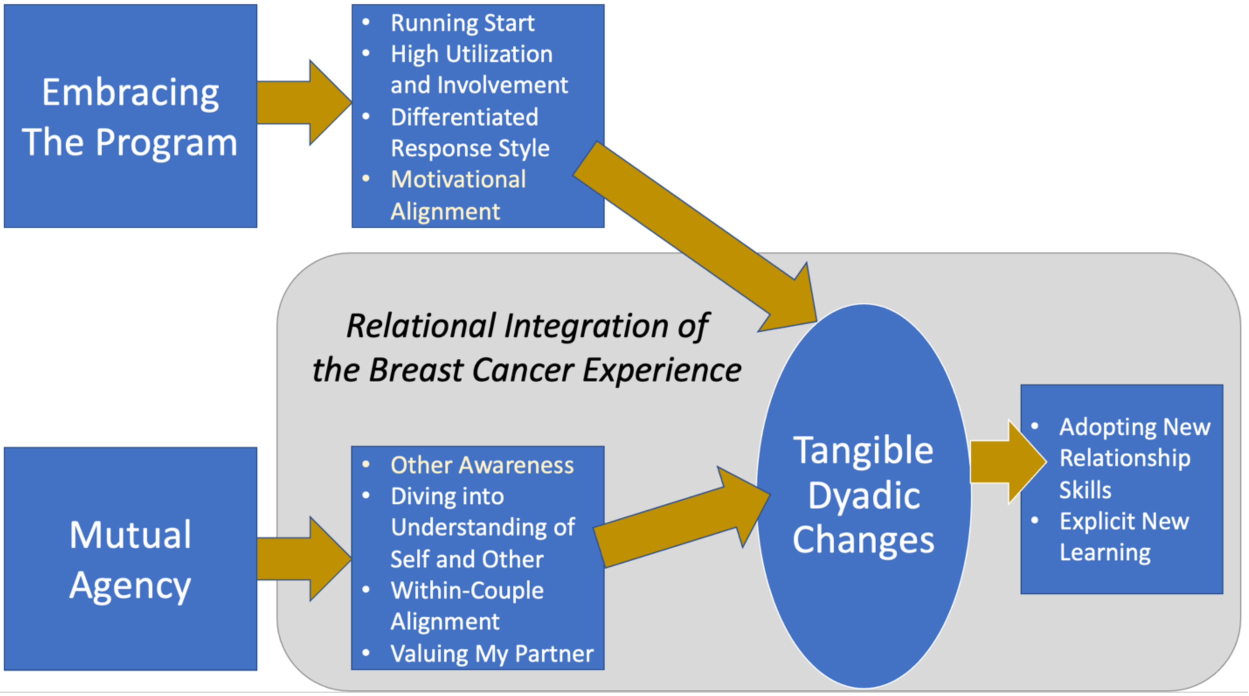
Table 3. Category Frequencies Table

*Participant representation across categories*

| **Categories and sub-categories** | **Successful Couples** | | | **Unsuccessful Couples** | | |
|---|---|---|---|---|---|---|
| | 119 | 213 | 307 | 107 | 305 | 315 |
| *Embracing the Program* | | | | | | |
| Running Start | ■ | □ | ■ | □ | ■ | □ |
| High Utilization and Involvement | ■ | ■▨ | ■ | □ | ■▨ | ■ |
| Differentiated Response Style | ■ | □ | ■ | □ | ■ | □ |
| *Mutual Agency* | | | | | | |
| Diving into Understanding of Self and Other | ■▨ | ■ | ■ | □ | □ | □ |
| Within-Couple Alignment | ■ | □ | ■ | □ | ■ | □ |
| Valuing My Partner | ■ | ■▨ | ■ | ■▨ | □ | □ |
| *Tangible Dyadic Changes* | | | | | | |
| Adopting New Relationship Skills | ■ | ■▨ | ■ | □ | □ | □ |
| Explicit New Learning | ■ | ■ | □ | ■▨ | ■▨ | □ |

*This table shows frequencies of categories by couple. A black rectangle indicates that both partners endorsed a given category. A grey and black rectangle indicates that one partner endorsed a category, and the partner did not. A white box indicates that both partners did not endorse the sub-category.

*Figure 7. Synthesized (Rational and Empirical) Model of Dyadic Success within Couplelinks*



## Discussion

The findings of this task analysis investigating poor and successful dyads participating in Couplelinks—an online intervention for young couples facing BC — revealed contextual and process-oriented mechanisms of change, in both directions of receiving benefit (or not) from the intervention. This research addresses the need to support couples, given that distress is pronounced among younger couples (Acquati & Kayser 2019; Ahmad et al., 2015). The intervention was designed with the knowledge that the toll of cancer often erodes partnered relationships. The accessibility of an online intervention allows for greater reach and independent movement through the intervention at the couple's own pace, with the assistance and guidance of a facilitator. What was needed at this juncture, following the Couplelinks RCT results, which showed modest effects for dyadic coping and no effect for relationship adjustment, was a deeper understanding of how couples learn from the program and improve dyadic outcomes, namely relationship adjustment in this case. With these a priori goals in mind, what was ascertained from the analysis is a model of change based on a hypothetical mapping(rational model) and observation (empirical model) analyses, which can be used to improve Couplelinks and move toward building a theory of dyadic success for YWBCs and their partners.

From our sample of six cases, it is important to note the baseline relationship adjustment scores to determine if the couples' pre-intervention scores were a factor in their relative success in the program. As a small sample, the couples were in the distressed range. R-DAS scale scores of 47 and below indicate relationship distress. While the trend we observed in the successful group was improvement from baseline to post-treatment, the fact that our groups started from a similar point of distress means that the mechanisms of change we identified were not connected to starting from different levels of distress prior to the intervention.

The theme of differing levels of utilization and involvement which emerged from our findings echoes what has been found in the online intervention literature, namely that engagement is an important factor for predicting treatment outcomes (Danaher & Seeley, 2009). Interventions for couples strongly rely on both partners' motivation and willingness to wholly participate, as well as their agreement in problem areas (Biesen & Doss, 2013). Online interventions are especially reliant on high engagement for success (Ianakieva et al., 2016; Danaher & Seeley, 2009). Earlier research in Couplelinks by Ianakieva (2015) identified "eBehaviours" that facilitators used to promote online engagement. It was noted that future research for this program should examine if engagement has intervention effects, specifically "it would be worthwhile to determine whether highly engaged couples benefitted more from the intervention when compared to non-engaged couples. This is an assumption underlying the rationale for the current analysis, but has yet to be supported" (Ianakieva, 2015, p.62). The results of the current analysis strengthens the view that couples who are attentive, involved, and high utilizers perceive greater benefit from the intervention. Thus, facilitators should indeed promote engagement in their role, and work to identify couples or individual participants who are not engaged to establish a stronger foreground for participation. Strategies to do so have been identified and empirically-observed in the aforementioned task analysis of Couplelinks (Ianakieva et al., 2016).

The 'Running Start' theme captures those successful couples who were ready to participate, 'with gusto,' which translated to increased motivation and, as such, better relationship adjustment post-intervention. We observed this eagerness in the successful group as opposed to the couples in the unsuccessful group who had a more passive relationship towards the intervention content. Strategies to encourage such an involved style from the start would contribute to a strengthened beginning to the intervention, thus paving the way for fruitful participation. Although the online modality of the intervention meets the need for greater flexibility for young, busy couples, we learned that the intervention requires a level of personal drive. We observed resistance towards the intervention among the unsuccessful couples.

The motivational interview (MI) style, defined by Rollnick and Miller (2013) as a collaboration between clinician and client to enhance motivation during therapy, has been proven effective to bolster the psychological processes of effort and commitment, and is used as an approach when resistance to change is occurring (Pudkasam et al., 2018; Rollnick & Miller, 2013). MI has been used in a variety of ways, for instance in traditional couples therapy for at-risk marital deterioration (Cordova et al., 2005), to improve outcomes for romatic partners in the health context, for example among individuals with chronic pain and their partners (Miller-Matero & Cano, 2015) and reduce sexual risk and drug use in HIV (Starks et al., 2018). Among cancer survivors, MI is evidence-based to improve lifestyle behaviours and psychosocial needs, for example in the areas of physical activity, smoking cessation, improved diet, and cancer stress management (Spencer & Wheeler, 2016). With respect to the current study, the importance of the facilitator being able to share with couples how to get the most out of the intervention stands to be important, using an MI framework wherein readiness for participation is tailored to the dyad. A prelude-type module to the intervention with two goals is thus recommended: (1) to orient couples to the intervention tasks and (2) to increase motivation among both individuals in the dyad and assessing for readiness. In addition, the development of a screening tool for couples during the recruitment stage may be beneficial to identify those couples who may be ready to engage versus those who are not currently in an action-oriented stage of readiness.

The ‘Within-Couple Alignment’ category speaks to the importance of both sharing similar goals for participation in the intervention, and a unified sense of couple identity, in order for couples to experience improved relationship adjustment. For the successful couple group, their similar connection to Couplelinks was emphasized. This speaks to the importance of couples being ‘on the same page’ when it comes to their shared goals and their hopes for participation. The Self-Expansion Model of Motivation and Cognition in close relationships may be used to understand why couples who benefitted were united in a range of intervention-related processes (e.g., how they partook in the intervention, their shared BC experience, and ways of coping). The Self-Expansion Model postulates that humans are driven to grow and increase their efficacy through their relationships (Aron et al., 2003). The theory has two components: (1) the motivational principle- defined as making efforts to “increase resources, perspectives, and identities in order to enhance ability to accomplish goals” (p.91) and (2) the inclusion of other-in-the-self principle- defined as “treating another person’s resources, perspective, and identities as if also one’s own” (p.91). Those dyads who were aligned demonstrated the motivational principle, in that they committed to relationship enhancement by taking up the Couplelinks principles and navigated the intervention as a shared unit, progressing together and in sync. Moreover, we saw evidence of ‘self-in-other’ when couples articulated just how similar and kindred they felt in their cancer experience. For example, those male partners who integrated their partner’s perspective into his own understanding of the BC experience were ‘sympatico’ and thus were seen in the successful group. Fergus & Reid’s (2001) concept of “We-ness” relates to the importance of a collective reality and mutual identity at play within the successful group. The phenomenon of “We-ness” refers to the process of co-creation of a new, shared couple identity. For those couples in the successful group, they demonstrated a deeper level of integration with one another, as evidenced in the ‘Alignment’ and ‘Diving Into Understanding of Self and Other’ categories. Indicators of a couple’s “we-ness” lies in their capacity to work together and their interpersonal sensitivity to one another (Singer & Skerrett, 2014), as evidenced by couples who learned to attune to one another throughout the intervention. Overall, the results of this study helped us to ascertain markers of intervention success leading to greater adjustment; namely, that couples are intertwined in a mutually beneficial way, share the same goals for participation, and know their couple identity well, while simultaneously striving for growth.

A key finding from this study is the importance of the principles taught and learned by couples in Module #3- “Creating Connection.” In this module, couples learn about the concepts of ‘turning towards’ and ‘turning away’, to help partners build self and other awareness of ‘bids’ for connection (Gottman & Gottman, 2008). Couples were then asked to track and record their own ‘turning toward’ and ‘turning away’ behaviours daily. These relationship behaviours, or in other words, negative and positive interaction patterns, are part of Gottman & Gottman’s (2008) “Sound Relationship House” theory of well-functioning relationships. According to this theory, the goal of learning relationship behaviours is for the individual to reflect on their ability to meet their partner’s needs and to ultimately increase their positive interactions. Research shows that satisfied couples have a greater ratio of positive exchanges to negative ones, and by recognizing the partner’s bids for emotional connection and knowing one’s own bids, the couple can smoothly connect (Gottman, 2011). In the present study, the couples in the successful group essentially ‘took to’ the Creating Connections Module (Module #3), and demonstrated their capacity to reflect on their own relationship behaviours towards their partner. Interestingly, in the successful group, there was one outlier couple who were not as aligned from the start. The male partner was not as invested in the intervention as his female partner. However, his interest and uptake peaked in Module #3, which led to improved engagement for future modules. For him, the act of looking inward and monitoring oneself became a new skill to integrate into the relationship. Of all six DLMs, this exercise embedded in Module 3 appeared to be the most 'potent' with respect to couple success. Knowledge of specific module efficacy is important when researching the utility of online psychosocial care. We know that it has greater accessibility and flexibility, especially for young couples (Ahmad et al., 2015), Thus, clinicians who are targeting relationship functioning within cancer care may recognize the desirability of this module as a brief, valuable skill to incorporate into their treatment plans and/or relationship interventions. Moreover, developers of such programs or practitioners offering time-limited sessions to partnered dyads may benefit from presenting this skill early on, to increase motivation. Given that the Couplelinks RCT (2021) showed modest effects that were not maintained post-treatment, future studies may investigate if the Creating Connections Module contributes to greater improvement of relationship adjustment using statistical outcome methods.

## Limitations and Future Directions

The results of this study should be considered alongside its limitations. A classic task analysis calls for empirical observation of therapeutic tasks as they are occurring to capture the 'unfolding' process. For example, watching therapy tapes, although a past event, still allows the researchers to witness a dynamic phenomenon at play. In this study, however, improved relationship adjustment was analyzed via asynchronous sources. Although some task analyses may use session transcripts or interviews (Pascual Leone et al., 2009), we relied on primarily past-reflection, written sources such as the module feedback. Some between-couple and intervention factors that may have occurred to drive change may therefore be absent. In general, research in online asynchronous interventions is limited and more research is needed to capture change mechanisms using this modality (Ianakieva et al., 2016). Also, we should consider our sample selection, which relied on looking at general trends (visual inspection of the data) over time on the R-DAS to discriminate between successful and unsuccessful cases. We used a method of triangulation to validate our sample, however, future studies would benefit from looking at statistical significance across different outcome measures. As well, our findings are based on a sample of 12 individuals (six couples)- the prototypical number for a task analysis- for the purpose of a rich and detailed observation. Considering that this task analysis did not have a validation phase, the findings are not generalizable to the greater population of young couples with BC, rather the results apply to the Couplelinks intervention itself. Furthermore, our sample was not diverse in race, culture, and sexual orientation, and thus future research for this intervention should include diverse and marginalized populations. The Couplelinks RCT results offer a generalizable framework to draw from as the sample size was adequately powered.

## Conclusion

The current investigation provides a de-constructed analysis (or ‘reverse engineering’) of the Phase III trial of the Couplelinks intervention, using a task analysis psychotherapy process method. Following the RCT findings, the next step was to deepen our knowledge of the mechanisms driving the observed changes in dyads in both positive and negative directions, culminating in a model that applies to intervention success. Fundamentally, we found a detectable pattern between those couples who benefitted versus those who did not. The initial distinction was found in an early stance in the intervention. For successful couples, high motivation, utilization, and thoughtful participation laid the groundwork for efficacious uptake of the intervention teachings. Also, the capacity to reflect on one’s unique couple identity before and after cancer helped couples to connect with one another, thereby contributing to benefit. A strong indication of successful change was the ability to learn new elements about self, the other, and the couple. Evidently, the couples who found ‘newness’ from the intervention and practiced skills that are known to promote good functioning within couples had improved relationship adjustment. In conclusion, the knowledge of the factors that coincide with improved outcomes post-treatment allows for intervention improvement at a granular level, and theory-building in online relationship support for partners in the cancer context at a broader level.

## Final Conclusions: Clinical and Research Implications

The negative, psychological impact for women diagnosed with BC before middle age is distressing and long-lasting. Overall, younger women (defined as being diagnosed by age 50 years) do not have encouraging biological and psychosocial outcomes compared to older women following treatment. The partnered relationships of YWBCs also tend to suffer in the years following diagnosis and treatment. Although the availability of clinical and community care for YWBCs has grown over the past 15 years, the advent of these interventions requires further examination, and still, more research is needed in this area to streamline age-related, psychosocial support. This two-study dissertation contributes to the growing body of research looking at specialized, YWBC care. Study one took a bird's eye view of the present day YWBC supportive care arena. Study two examined a specific intervention (Couplelinks) for YWBCs and their partners to identify change mechanisms and promote theory-building within said intervention.

The first study provided a broader overview of the YWBC programmatic landscape within the academic and community realms using a conjoint scoping review and environmental scan method. We found that there is high focus on educating this group on treatment side effects and addressing fertility concerns. There are clear differences in the types of programs and resources offered to YWBCs based on their origin of development i.e., community or hospital-based. There are opportunities for further partnerships between both domains. The findings of this study may be used to guide future systematic reviews in this area. For researchers and program developers, this study may bridge the outputs between two domains that both serve YWBCs. It is useful for each domain to have knowledge of the other so that they may draw from and learn about varying models of praxis and YWBC after care. Clinically, providers may be able to recommend these resources to YWBCs based on their specific needs.

The second study demonstrated differences between two groups of couples who partook in the Couplelinks intervention—an online, relationship enhancement intervention designed for romantic partnerships where the young woman has undergone treatment for BC. We found a discernible pattern on a measure of relationship adjustment between couples who fared better versus those who did not. What distinguished successful couples from those who did not improve on the intervention was their pre-intervention stance of commitment and engagement, their knowledge of one another and their collective BC experience, and finally, a sense of novelty (with respect to their unique couple identity and the relationship skills they developed) that emerged from partaking in the intervention. With this knowledge of change mechanisms, we are able to offer insights to improve on the intervention and work to facilitate favourable outcomes for YWBC couples. Furthermore, these findings may be used to build on existing theories and models for promoting positive change in cancer couple interventions.

Together, these two studies examined ‘the forest’ (Study 1- broad YWBC support care) and ‘a tree’ (Study 2- one intervention designed for YWBCs). A comprehensive review of the existing resources and comparing/contrasting their development models has provided areas for improvement and future directions for YWBC supportive care. Moreover, burrowing into the Couplelinks intervention, specifically examining what accounts for good and poor outcomes helps to improve couple-based programs within cancer. The phrase, “the minority group with the majority of need” (Ahmad et al., 2015,p.271) still rings true, and so our express hope was to maximize and magnify the knowledge pool of YWBC resources, meaningfully.

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