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Quality-of-Life Indicators for African American and European American Long-term Survivors of Early-stage Breast Cancer

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Abstract

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Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

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Abstract

This meta-analysis investigated the difference in perceptions of health-related quality of life (HRQOL) among long-term early-stage breast cancer survivors (BCS). The comparison was between African American and European American women. Initial pilot searches suggested that enough studies existed for a meaningful meta-analysis of a BCS population at least 5 years post diagnosis. Only studies using the outcome measure HRQOL were included in the study; this yielded an initial sample of 212 study reports, with 56 reports entering the coding phase of the process. African American women were grossly underrepresented in this set of studies in comparison to the overall breast cancer population. Separate analyses of Medical Outcomes Study 36- Item Short- Form Health Survey, Quality of Life-Cancer Survivor and Quality of Life Index – Cancer Version III instruments were executed. However, no stringent comparison across instruments of the difference between the HRQOL of African American and European American women was possible. When African American women were included in the populations, researchers often did not report their data separately but rather included their data in an overall population and thus differences were masked. The data that were available, including qualitative studies for African American women, suggested that there was a lower perception of the quality of survival in some areas for African American women. These differences suggest the need for greater attention to the physical components of African American BCS. The results point to a need to improve African American participant recruitment in research and to use online databases as a results repository to improve data availability for analysis.

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Dedication

For the sisters who walk the long road of living with breast cancer.

For the men who support them, as the men in my life did in doing this work, John, Geoffrey, and Bruce, providing motivation, inspiration, and love.

For the women who hold them up, as the sisters of my heart did for me, Pat, Marti, Susie, Judy and Jess giving love and refuge in adversity, perspective, wisdom and sometimes a good swift kick in the pants.

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Without Dr. Ragsdale I would not have had the courage to attempt a meta-analysis or to continue to keep on until it was done, without Dr. Hendricks Noble I think I would have quit in the first year, and without Dr. Milo, I wouldn't have even got to a dissertation. Many, many thanks.

Dr. Borenstein was kind enough to email clarifications on his book when I was confused and desperately trying to learn how to do a meta-analysis. His kindness helped me find my way through and I am truly grateful.

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Chapter 1: Introduction to the Study

Background of the Study

Most women diagnosed today with early-stage breast cancer will survive for more than 5 years (American Cancer Society, 2011). As of 2012, the 5-year relative survival rate amongst women diagnosed with localized breast cancer was 98.4%, with a difference between African American (92.7%) and European American women (99.2%) in long-term survival (Howlander et al., 2012). The approximately 2.8 million women living with breast cancer in 2012 were primarily early-stage survivors from all races (American Cancer Society, 2010). More than 50% of women diagnosed will be diagnosed with Stage I or II breast cancer, with that number rising to over 80% if a Stage 0 (in situ) diagnosis is included (Ries, Eisner, & Kosary, 2001).

The American Cancer Society (2010) estimated that around 230,000 women in the United States would be diagnosed with breast cancer in 2011, of whom almost 12% (estimate 26,840) would be African American women (Susan G. Komen Circle of Promise, 2009). Extrapolating from the data presented above, a little over quarter of a million BCS were African American, and about 1.8 million were European American, with the remaining 8% of survivors made up from Asian, Native American and Hispanic identified women (Howlander et al., 2012). There has been evidence of disparity in treatment of breast cancer (Bradley, Given, & Roberts, 2001; Dignam, 2000; Li & Malone, 2003). While socioeconomic status SES can account for some of these differences (American Cancer Society, 2011), evidence has emerged that even in

localized breast cancer there may be impact differences (Vin-Raviv et al., 2013) between African American and European American women.

English-speaking women of European descent, in the United States or the United Kingdom, have constituted the majority of the population studied in post-diagnosis and treatment research. Women identified as African American have been less studied (Hulka & Moorman, 2001; Thompson et al., 2008). The percentage of African American participants was lower in the 22 studies in the final stage of this analysis (8.12%) than in the BCS population in general. Nine of the final papers did not report racial breakup of participants, and there was little reporting of data for African American and European American populations separately. African American women have often been underrepresented in clinical trials (Cross, Harris, & Recht, 2002). African American women have also been underrepresented in published psychosocial research, as have other women belonging to minority groups and who do not speak English (Thompson et al., 2008).

Focus on Long-term Survival

The treatments applied to cancer, even its early-stages, are powerful and potentially toxic (Lipscomb, Gotay, & Snyder, 2004a). There is a growing awareness that impacts from treatment can develop months and even years after primary treatment has ended (Aziz, 2007; Hewitt, Greenfield, & Stovall, 2005). These impacts can include physical symptoms such as pain (Ashing-Giwa, 1999a; Carver, Smith, Petronis, & Antoni, 2006), cardiotoxicity (Darby et al., 2013), distress suffered in response to the functional impact, and social and financial consequences related to treatment and survival

(Aziz, 2007; Hewitt, Herdman, & Holland, 2004; Thewes, Butow, Girgis, & Pendlebury, 2004). The cost of treatment and the cost of recovery increase if additional services are required to cope with the impact. The focus of this study on long-term survival was a response to this growing awareness of consequences that occur long after treatment has ceased, as well as the increasing population of women who survive early-stage breast cancer.

Racial Category and Survival

European American women are more likely to receive a breast cancer diagnosis. African American women have a higher chance of dying from the disease than European American women (Hewitt et al., 2004, p. 19), with an average 5-year survival rate of 78% versus 90%. Later stage detection and more aggressive tumor characteristics lead to poorer stage-specific survival (American Cancer Society, 2010, 2011; Hewitt et al., 2004). Comorbid illness and social and demographic characteristics also contribute to survival differences (Hewitt et al., 2004, p. 19). For example, African American women have a higher chance of being diagnosed younger and at a later stage of cancer, with 55% diagnosed above Stage I compared to 45% of European American women (Cross et al., 2002). Cross et al. (2002) argued that African American women are more likely to be impacted by "lower educational level and income, cultural beliefs, lower insurance status, diet, and screening practices" (p. 1990), all of which have a potential impact on when a woman presents for diagnosis. They also argued from their review of the literature that there may be treatment differences in the treatment given to African American women and that this may be due to differences in SES. Racial identification may be used a proxy

for SES (Cross et al., 2002; Krieger, Williams, & Moss, 1997). While a significant number of the studies reviewed by Cross et al. (2002) identified characteristics of SES as having predictive value of survival of the population under study, in clinical trials where the treatment of patients was homogeneous for women of the same disease stage, African American women had a worse prognosis with estrogen receptor negative cancers (Cross et al., 2002). Women of other races in the United States have had a lower incidence and lower mortality rate than either European American or African American women (Howlander et al., 2012).

This study set out to understand, from current research, if there was a perceptible difference in the experienced long-term survival (greater than 5 years; American Cancer Society, 2011) between African American women and European American women who survive early-stage (localized) breast cancer. The primary comparison in this review was between Americans of African racial heritage, also referred to in some studies as Black and in this study as African American, and Americans of European heritage, or White, also named Caucasian or, as in this study, referred to as European American.

A brief review of the literature on breast cancer survival follows in the next section. The nature of the study, the problems under investigation, and the hypotheses tested follow that section in appropriately headed sections. Both meta-analysis and outcomes assessment, particularly HRQOL, are discussed briefly as the theoretical base. The chapter concludes with the limitations, assumptions, and considerations of the study including the possible implications for use of the information.

Research Findings

Breast cancer and its treatment have been the focus of the largest body of knowledge about adult cancer survivors (Aziz, 2007). Much of that research focused on the physical and medical aspects of surviving. A growing focus in both medical and psychological research is in outcomes research, which is directed at understanding the results of health care practices on "final end points that matter to decision makers: patients, providers, private payers, government agencies and society at large" (U.S. National Cancer Institute, as cited in Lipscomb et al., 2004a, p.1). Health-related quality of life (HRQOL) is one of these end points and was the focus of this review. Several interrelated domains were of interest, with different instruments having a focus on different areas of survival (Ashing-Giwa, 2005b; Ferrans, 2004). Aside from the physical arena, investigators usually considered mental, social, spiritual, and sometimes economic areas (Ferrans, 2004) with the patients' self-assessment being the only measure (Zebrack, 2004).

There is a growing understanding that the quality of life can also impact physical survival (Montazeri, 2008). Two reports from the Institute of Medicine of the National Academies consolidated much information on cancer survival in general (Hewitt et al., 2005) and detailed issues relating to psychosocial aspects of survival in breast cancer (Hewitt et al., 2004). The Susan G. Komen for the Cure (n.d.) research spending (on cancer control, survivorship, and outcomes) was 7% of their total research budget in 2008 and 2009, up from 1% in the years prior to 1996. Of the 777 research initiatives that a search of breast cancer on the National Institute of Health site returned (as at December

15, 2012), 21 were, based on their descriptions, related to survivors (National Institutes of Health, n.d.).

Breast cancer research can be roughly categorized into research focused on the period from diagnosis to the end of treatment, research focused on the first 5 years of survival, and long-term survival past the 5-year transition point (Thewes et al., 2004). Thompson et al. (2008) pointed out that early-stage and end-stage components of the cancer trajectory have been well researched. They identified that the impact of cancer as a chronic disease requires more research and attention, including the day-to-day issues of living with the symptoms as well as chronic comorbidities that may be treatment effects or existing conditions such as diabetes, arthritis, and weight gain (Thompson et al., 2008).

The majority of the population who has participated in breast cancer clinical trials and psychosocial research has been from the United States or to a lesser extent the United Kingdom, of European descent, English speaking, and of moderate to high SES (Hulka & Moorman, 2001; Thompson et al., 2008). Some research has been conducted with women who were not European and who did not speak English, focused especially at long-term survival and quality of life (Ashing-Giwa, Tejero, Kim, Padilla, & Hellemann, 2007; Ashing-Giwa et al., 2010, 2004; Ashing-Giwa, Padilla, Bohórquez, Tejero, & M. Garcia, 2006; Chan et al., 2006; López, Eng, Randall-David, & Robinson, 2005; Lu et al., 2009; Neyt & Albrecht, 2006). There remains a lack understanding of how women in minority subgroups experience long-term survival and how it differs from their more studied counterparts.

Gaps identified in the research by narrative review include a lack of research about how cancer and cancer treatment burdens survivors long term (Boyle, 2007) and research into underserved populations that may include the elderly, those in lower education and income segments, in remote geographic locations, an in minority populations. (Aziz, 2007)

Age and survival. Breast cancer risk increases with age. Between 2002 and 2006 95% of new cases of breast cancer and 97% of deaths occurred in women over 40, with the highest incidence rate recorded for the age group 75 to 79 (Centers for Disease Control and Prevention [CDC], 2010). The median age of diagnosis was 61 years (CDC, 2010). Older women have been underrepresented in studies (Thompson et al., 2008). Underrepresentation means that how older women survived breast cancer was less visible in the work that was available. Authors of the studies in the current meta-analysis did not identify data separately for different age groups within racial designations.

SES and survival. Researchers have pointed to a robust correlation between health and SES (Daly, Duncan, McDonough, & Williams, 2002; Krieger et al., 1997; Liberatos, Link, & Kelsey, 1988; Oakes & Rossi, 2003). SES has also been shown to have correlations with the occurrence and mortality associated with breast cancer (Braveman et al., 2005; Kreiger, 1990) and with breast cancer survival (Krieger, 1992). Cross et al. (2002) found that when controlling for tumor characteristics and age, SES was often a better predictor of outcome than race. Where single institutions were involved, with the likelihood of consistent treatment increased, race usually ceased to be a predictor of survival (Cross et al., 2002). Where studies were of a heterogeneous

population, or where SES was inferred from living locale or other surrogates for SES rather than self-report, race tended to become a predictive factor (Cross et al., 2002). Regardless of race, women with lower SES tended to present with worse tumor pathologic factors, more advanced disease, and lower survival likelihood in clinical trials (Cross et al., 2002) and SES consistently emerged as a risk factor for breast cancer (Hulka & Moorman, 2001).

Depending on the instruments used, one domain of interest in HRQOL has been social/socioeconomic influence (Ashing-Giwa, 2005b). The studies in the meta-analysis did not report socioeconomic data.

Problem Statement

The population of BCS of more than 5 years since the primary treatment ceased has been growing (Hewitt et al., 2005; Howlander et al., 2012), along with evidence of late occurring medical and psychosocial impacts from both the disease and treatment (Hewitt et al., 2005). Consolidating research on how women survive long-term had the potential to give clearer direction to future research and action to support those women.

African American women who survive early-stage breast cancer make up about 12% of the population of early BCS, and European American survivors make up around 80% of the survivor population (American Cancer Society, 2010; Susan G. Komen Circle of Promise 2009). There has been evidence of treatment and impact differences (American Cancer Society, 2011; Bradley et al., 2001; Hewitt et al., 2005; Li & Malone, 2003; Vin-Raviv et al., 2013), some of which may be accounted for by socioeconomic factors (American Cancer Society, 2011).

There is a body of research into long-term survival from localized breast cancer conducted using the outcomes assessment measure HRQOL (Lipscomb et al., 2004a). Use of the techniques of systematic review and meta-analysis allowed a comparison of the different research (Cooper, Hedges, & Valentine, 2009; Lipsey & Wilson, 2001). The HRQOL of long-term BCS had the potential to indicate differences that could inform ongoing decision making (Chalmers, 2007) about the development and provision of support for women of different racial backgrounds.

The dependent variable, HRQOL, is a composite measure that is used in an attempt to encompass the multiple dimensions into a manageable variable that can be used to show how survival from a disease can be characterized and described. While different instruments have been used, overall it provides a workable construct with which to frame the differences (Lipscomb et al., 2004a). A more detailed understanding of the impact of breast cancer can be achieved by examining HRQOL within its composite domains (Avis, Ip, & Foley, 2006; Cella et al., 1993; Ferrans, 2004; Osoba, Aaronson, Zee, Sprangers, & te Velde, 1997; Ringdal & Ringdal, 1993; Schag, Ganz, & Heinrich, 1991).

The independent variable, race, includes the categorization of European American (White), African American (Black), Asian American/Pacific Islander, Hispanic/Latino, and American Indian/Alaskan Native, as used in the American Cancer Society (2010, p. 4) report on cancer survival. Researchers variously referred to European American, Caucasian, or White study populations, or to African American or Black study

populations. In this study, only the designations African American and European American were of interest.

While disease stage has a significant impact on survival from breast cancer, I bounded the population under study to those with local or early regional disease at diagnosis (Stage 0, I or II). Primary studies that included participants who had recurrent cancer or later stage cancers were excluded.

Purpose of the Study

The purpose of the study was to identify from the body of research if there were significant differences correlated with racial categorization in the experience of long-term BCS and to compare the effects specifically between African American and European American populations. Understanding how current researchers have differentiated the experience of women in the population of interest had the potential to lead to a better understanding of the support and help these women need, or if the research was inadequate to be able to make that determination. Understanding the adequacy of research had the potential to lead to further research in targeted areas, with more targeted populations, or the ability to focus funding where it is most required.

Nature of the Study

The study undertaken was a meta-analysis of the research using HRQOL as the outcome measure (dependent variable) of long-term survival from early-stage breast cancer. The focus of the study was to understand the evidence for differences in experience between women of African American and European American racial designation (independent variable).

It was planned to examine the instruments used to measure HRQOL in the subject studies as a moderator on the effect size (Borenstein, Hedges, Higgins, & Rothstein, 2009). If data were available from the selected studies, I had planned to analyze age, SES, and study characteristics.

Research Questions and Hypotheses

The research questions associated with this problem statement are as follows:

1. Compare the effects of survival for more than 5 years post treatment on HRQOL of African American Breast cancer patients diagnosed with Stages 0-II with those of patients of European American racial identification?
2. Is enough data available in the population of studies to observe the impact of age on the effect size?
3. Is there enough data on SES in the population of studies to identify its impact as a moderating variable?
4. Can the choice of HRQOL instruments be identified as having an impact on the effect size seen in the research?
5. Can subgroup analysis identify differences in components of HRQOL?
6. The null hypothesis for the study is that the mean effect size is zero (random effects model; Borenstein, Hedges, Higgins, & Rothstein, 2010).

The Standardized Mean Difference (SMD) of HRQOL is the effect size being measured in this meta-analysis.

Theoretical Base

Meta-analysis

Meta-analysis is "the statistical analysis of a large collection of analysis results for the purpose of integrating the findings" (Glass, as cited in DeCoster, 2004, p. 2). Lipsey and Wilson (2001) explained that this form of analysis is another approach to survey research except that it is the research reports that are surveyed rather than people.

Meta-analysis has some significant advantages when trying to synthesize and consolidate data across a significant body of work. As a structured technique, it requires the documentation of the process used so that in theory another researcher could take the same body of work and reach the same conclusions (Lipsey & Wilson, 2001; Randolph, 2009). The use of effect sizes means that a more nuanced synthesis is possible with the ability to test findings that differ across research reports (Lipsey & Wilson, 2001). Using a meta-analysis approach may allow relationships across studies that would not appear in a narrative approach, and by using the systematic coding and management approach of meta-analysis it is possible to consider a large number of studies (Lipsey & Wilson, 2001).

Outcomes Assessment

According to Lipscomb et al. (2004a), "Outcomes research may be defined generally as the scientific field devoted to measuring and interpreting the impact of medical conditions and health care on individuals and populations" (p. 1). This relatively young field (Ferrans, 2004; Lipscomb et al., 2004a) continues to evolve, but

HRQOL has become a key way that the impacts of chronic disease can be monitored over time with some sensitivity to the experience of the individual (Lipscomb et al., 2004a).

There are many instruments that may be used to measure different components of HRQOL (Erickson, 2004; Feeny, 2004; Ferrans, 2004; Zebrack, 2004). Depending on the research question, the researcher may choose instruments that best suit the purpose (Ferrans, 2004). General instruments designed to measure people who are not ill or who are ill without specific reference to a particular condition (Erickson, 2004), or instruments specific to the type of illness or to the site of illness (for example, breast cancer; Ferrans, 2004), or a specific instrument for measuring an outcome (for example, a standardized instrument for measuring depression; Zebrack, 2004) are available.

Within the overall concept of HRQOL, there may be a focus on one or more domains of interest (Ashing-Giwa, 2005b; Ferrans, 2004). The physical, mental, and social are those usually considered the minimum number of domains included (Ferrans, 2004). In some studies authors chose domains like the spiritual, socioeconomic and cultural components to more clearly identify the differences in minority perceptions of illness (Ashing-Giwa, 2005b).

Definition of Terms

Health-related quality of life (HRQOL): HRQOL is a patient-reported, subjective assessment or evaluation (Lipscomb et al., 2004a) of the experience and impact of illness on a person (Ashing-Giwa, 2005b) that may or may not have an overall global well-being assessment (Lipscomb et al., 2004a, p. 7). The domains that were of interest in this study were physical, psychological/emotional, economic, spiritual, and social (Ferrans, 2004, p.

15; Ferrans, Zerwic, Wilbur, & Larson, 2005). These domains can often be aggregated to provide an overall score if one is not part of the measure (Powe et al., 2007). HRQOL may change over time (Cella, 1994).

Long-term cancer survival: "Individuals who are5 or more years beyond the diagnosis of their primary disease and embody the concept of permanent survival" (Aziz, 2007, p. 418).

Late effects: There is recognition that long-term survivors of cancer, including breast cancer, may have impacts and impairments from treatment, including drugs, which do not appear until long after treatment is complete (Aziz, 2007).

Long-term effects: Side effects or complication of treatment that have an impact on a patient's life, either in the ability to function or in additional medical treatments for which some adjustment is required from the patient. These may appear months or years after treatment and may persist for many years (Aziz, 2007, p. 418).

Assumptions

Data provided from the sources were accurate. All processes for acquiring data were identified. Sources and approaches were visible, as is required by the process of meta-analysis. Accuracy of the data, statistics, and information provided in the studies could not be proven true and accurate, especially if data from nonpublished sources could be included in the study.

Limitations

The approach was based only on quantitative research so that studies of a qualitative nature could not be included (DeCoster, 2004; Lipsey & Wilson, 2001). By

definition, systematic review and meta-analysis require an exhaustive search of the literature. Unpublished sources may contain findings where the significance of the results was low and there was little support for publication. Despite best efforts to include all relevant sources, it was reasonable to expect that some material that would change or influence the results may not be included. Publication bias, the more likely publication of significant results, influenced the published data. Searches that included grey literature and other non-journal resources were my attempt to overcome this. The process of the search appears in Chapter 3.

The operational definition used for the outcome measure of this study was the effect measured by HRQOL instruments. HRQOL measures vary, appropriately depending on the stage of the cancer trajectory that is being studied. While I assumed that researchers would have used appropriate measures, an analysis of the differences in effect sizes with different instruments was planned.

There was no attempt to review the literature focused on the validation or proposal of interventions, treatment options, or approaches to preventative strategies.

Research into long-term breast cancer survivorship has primarily been focused in the United States. Because of the focus on racial background in this current study, studies of subjects not from the United States were excluded from this work. This work is by its nature only generalizable within the population of BCS in the United States and within the defined groups of African American and European American.

Two issues that have emerged in research into long-term and late effects of cancer treatment that I did not directly address in this analysis were the as follows. The first was

an understanding of how the BCS population differs from a matched cohort of women who have not had breast cancer, although where possible data were compared to population norms for the instrument. The second was how the evolution of treatment modality has been changing the survival pattern of breast cancer (Stein, Syrjala, & Andrykowski, 2008).

The second of these questions had an impact on the data that was included, as women in the target of the analysis may have been through many variants of standard treatment. Over the last 50 years, treatment choices have changed dramatically from full mastectomy to lumpectomy and chemotherapy and radiation, to lumpectomy and radiation and longer term follow-up therapy (Reynolds, 2012). It was likely that as treatment has become less toxic, so the long-term effects may be less. Studies used as the basis for this analysis rarely contained the data needed to separate out and control for the effects of this variable.

Delimitations

The review focused on the research conducted and the findings that have been published, using HRQOL instruments as the outcome measure in long-term breast cancer survival. I examined the research that has been conducted into the experience of women surviving breast cancer. I specifically excluded medical components, treatment regimens, physical impacts, and comorbid disease, as variables in the analysis. These can all contribute to the quality of life of survivors.

The focus was on long-term survival without recurrence, so recurrent breast cancer and the associated trauma was excluded from the discussion. Additionally, the

review focused on the population with a diagnosis of local or early regionalized stage of the disease as the survival rates and the possibility of living disease-free was more likely in that population(American Cancer Society, 2011; Hewitt et al., 2004; Howlander et al., 2012).

To be included in this review, a study had to focus on participants who had been out of active treatment for more than 3 years, or 5 years post diagnosis. This long-term timeframe was specifically chosen because of the large number of women surviving through this period.

There was no attempt in this study to draw causal relationships between variables within HRQOL and breast cancer history, experience, or demographics.

Significance of the Study

Interventions targeted at reducing psychosocial distress have been valuable for patients identified as distressed but of less value if the clients are drawn from the survivor population without targeting (Sheard & Maguire, 1999). A more granular understanding of the differences between African American and European American BCS may allow for better targeting of those who need support.

There has been significant research and integration of that research into how race, age, and SES impact the incidence, survival rates, and mortality associated with breast cancer (American Cancer Society, 2011). While there have been several literature-based reviews (Bigby & Holmes, 2005; Chopra & Kamal, 2012; Gotay & Muraoka, 1998; Howard, Balneaves, & Bottorff, 2007; Meyerowitz, Kurita, & D'Orazio, 2008; Montazeri, 2008; Phillips & Bernhard, 2003; Powe et al., 2007), no meta-analysis was

identified in the search; while conclusions have been drawn, the size and direction (Ellis, 2010) of the effect was at best subjective (I. Wilson, 2004).

Identifying and integrating the research that has been conducted and understanding where significant differences occurred would have supported a better understanding of services that may be required to support this population. It had the potential to differentiate different approaches to managing the impact of breast cancer in the long-term survivor. The outcome of this analysis was planned to provide information that would allow a more tailored approach to these women by synthesizing research outcomes over the body of knowledge and identifying information about how these groups differ from current understanding.

An improved understanding of differences in the survival experience would have supported more effective planning of appropriate interventions and post-treatment care both in content and length. The detail of the difference was planned to provide support for change in lifestyle or care recommendations for long-term survivors. These changes could have had the potential to impact the quality and length of survival (Aziz, 2007) and support positive change in managing the psychosocial aspects of breast cancer survival and for the women who survive.

Summary

The difference in the experience of breast cancer survival in women of different racial background has the potential to inform more effective deployment of limited resources. The incorporation of research from across the survival spectrum using a meta-analytic approach potentially would have included even small studies in scholars' overall

understanding. Meta-analysis requires exhaustive documentation and visibility of process so that issues, problems, and gaps are visible in the data.

In the next chapter I discuss the literature currently available on long-term survival from breast cancer. The literature on the use of HRQOL and outcomes analysis as well as the current state of knowledge on the use of systematic review and meta-analysis are provided.

Chapter 2: Literature Review

Introduction

This review of the literature begins with an overview of BCS. A discussion of the use of HRQOL as an outcome measure for survival begins a section that looks at the body of knowledge about breast cancer survival as informed by the domains of HRQOL. I discuss how researchers on long-term HRQOL have distinguished between African American BCS and European American BCS as well as the findings related to the interaction with age and SES; I also explored the distinctions made in the literature. The final section of this chapter addresses the literature relating to systematic review, including meta-analysis that informed the methodology of this study and the issues and considerations associated with this approach.

Methodology

Literature searches were conducted using the Walden University online databases, using search arguments associated with breast cancer survival, including terms that relate to breast carcinoma and long-term survival. The research databases of the National Institutes of Health were also searched, and I built a database of articles and references. The number of studies was reduced by limiting the focus to longer term survival and to Stages 0 through II of breast cancer diagnosis. Two key reviews of breast cancer survival (Hewitt et al., 2005, 2004) provided a starting point for an overall view of the research focus and the development of a list of key researchers in the area of interest. More detailed research on racial categorization and the interaction with SES and health-related outcomes was initiated through an Internet search.

HRQOL is a complex theoretical variable that researchers have often used as a measure of the quality of survival (Lipscomb et al., 2004a). An Internet search was instituted to retrieve literature that related to the development of the concept and its application in survival research. In all cases, initial retrieval of published literature was followed by the development of an understanding of the key researchers in the area and the retrieval of additional literature referenced in key articles. When retrieving literature, I did not try to be exhaustive, but rather representative and informative of the state of the body of knowledge. In 2004, the publication of the work of Cancer Outcomes Measurement Working Group commissioned in 2001 by U.S. National Cancer Institute provided a critical synthesis of outcomes assessment, particularly using HRQOL (Lipscomb et al., 2004a). It included material from authors in the field identified from the literature search above and added depth to the understanding of the use of the construct and instruments both in overall cancer survivorship research and with the breast cancer population.

The search for methodological literature on systematic reviews and meta-analysis started from key texts on the subject (Borenstein et al., 2009; Cooper, 2009; Cooper et al., 2009; DeCoster, 2004; Ellis, 2010; Lipsey & Wilson, 2001; Rosenthal & DiMatteo, 2001; Rosenthal, 1995). It progressed using the bibliographies and further database searches, and I developed the bibliography used in both the literature review and to support the development of the methodology in Chapter 3.

In all subject areas, a snowball technique was used to broaden the search from references provided in seminal articles and publications.

Breast Cancer Perspective

Each year around the world about 1.1 million women are diagnosed with breast cancer, accounting for more than 400,000 deaths (Montazeri, 2008). In the United States in 2012 approximately 2.8 million women were living with a past diagnosis of breast cancer (American Cancer Society, 2011), almost a quarter of a million were African American (around 12%; Susan G. Komen, 2009). BCS are "the largest group of female cancer survivors" (Casso, Buist, & Taplin, 2004, Background section, para 2)

The incidence rate of breast cancer in non-Hispanic European American women has been higher than for African American women for all age groups except those younger than 40 years of age at time of diagnosis. African American women are more likely to die from breast cancer regardless of age (American Cancer Society, 2011, p. 4). Between 1980 and 1987 the rate of occurrence of breast cancer increased, and researchers thought that this was due to improved screening methods that allowed smaller tumors to be identified. The rate stabilized between 1987 and 1994 and then rose again to a peak in 1999. Between 2002 and 2003 the rate dropped by nearly 7%, likely due to a decrease in the use of hormone replacement (American Cancer Society, 2011). Among African American, women the rate rose until 1992 and has been stable since then (American Cancer Society, 2011).

The "American Cancer Society (ACS) defines cancer survivorship as beginning at diagnosis with cancer and continuing for the balance of life and views quality of life (QOL) as a key outcome" (Smith et al., 2007, p. 1). The National Coalition of Cancer Survivorship has used the same definition (National Cancer Institute, 2012). Long-term

survivors are patients who do not die in the 5 years after diagnosis (American Cancer Society, 2011). Better capability for detection and improved treatment of breast cancer means that the majority of the women diagnosed will become long-term survivors (Aziz, 2002; Ganz et al., 2002; Paskett et al., 2008). HRQOL has become an important area of research in this population (Ashing-Giwa, Padilla, Tejero, & Kim, 2004). The largest body of knowledge for adult cancers comes from BCS (Aziz, 2007), with much of that research focused on the physical and medical aspects of surviving (Ganz et al., 2002).

Cancer is considered a chronic disease (National Center for Chronic Disease Prevention and Health Promotion, 2012). As a patient continues through the trajectory, the stresses of treatment are often replaced with physical sequelae of treatment that may include ongoing side effects (Darby et al., 2013) that can have a negative impact on survivors' quality of life (Chopra & Kamal, 2012; Montazeri, 2008). Survivors may have to deal with the uncertainty of cancer recurrence (Deimling et al., 2006) and perhaps psychological distress and the disruption of social life, sometimes decades after treatment (Henderson, 1997). Around 10.2% of BCS will deal with physical issues, and about 5.9% of BCS will deal with continuing mental issues, similar to women who have not had breast cancer (Weaver et al., 2012). These sequelae may become "more problematic with increasing age" (Chopra & Kamal, 2012, p. 13). Most long-term survivors are more 60 years old because the rate of incidence increases in middle age (Mishel et al., 2005).

HRQOL

The dependent variable in this relationship is the experience of survival as measured by instruments focused on HRQOL. HRQOL is a composite concept used to

encompass the multiple dimensions of survival (Ferrans, 2004). HRQOL attempts to distinguish those components of experience of illness that are within the impact zone of the health system from those that are not (Ferrans, 2004). However, as Ferrans (2004) pointed out, when a woman is ill many aspects of her life, such as race, education, and SES, that are of interest in this study and that would otherwise not be part of the overall health assessment, may be influential in the outcome. A defining aspect of an HRQOL assessment is that the status is patient reported and is a subjective assessment or evaluation (Lipscomb et al., 2004a)

HRQOL measures are designed for specific populations and illness trajectory points as well as specific research requirements (Ferrans, 2004). There are generic measures that are not specific to cancer and may be applied across the health spectrum (Lipscomb et al., 2004a), for example, the Medical Outcomes Study 36- Item Short-Form Health Survey (MOS SF-36; Ware, Snow, Kosinski, & Gandek, 1993). General cancer measures, for example, the Functional Assessment of Cancer Therapy - General (FACT-G, Cella et al., 1993) or the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ C30, Aaronson et al., 1993) can be used regardless of cancer site (Lipscomb et al., 2004a). Measures that are specific to a cancer site like the FACT- B (Breast, Brady et al., 1997) are more used to identify patient concerns for that site, in this case Breast Cancer (Lipscomb et al., 2004a). Additionally some researchers choose standard instruments, for example, the Beck Depression Inventory (BDI, Beck, Steer, & Carbin, 1988) for outcomes assessment (Montazeri, 2008; Perry, Kowalski, & Chang, 2007).

Outcomes Assessment Using HRQOL

Much research into the impacts of breast cancer relies on the theoretical backdrop of HRQOL (Ganz, 2008). The concept of HRQOL encompasses "complete social and psychological being: the individual's performance of social roles, her mental acuity, her emotional state, her sense of well-being and her relationships with others" (Levine, 1987, p. 4). This concept goes beyond measurable and objective health outcomes and includes a person's expectations, attributions and perceptions. The measure is influenced by life experience, gender, and age so that the same health profile may result in very different HRQOL perspectives (Bloom, Petersen, & Kang, 2007). HRQOL attempts to measure the experience of the individual and is, by definition, patient reported (Lipscomb et al., 2004a).

HRQOL is usually constructed of physical, mental and social domains and may be expanded to include the economic and spiritual (Ferrans, 2004). The physical dimension is focused on the control or relief of symptoms, keeping function, and independence (Ashing-Giwa, Padilla, Tejero, & Kim, 2004; Ferrans, 2004; Powe et al., 2007). The psychological includes trying to deal with a life-threatening illness and includes emotional distress, the presence or absence of depression (Deshields, Tibbs, Ming-Yu Fan, & Taylor, 2006), anxiety (Powe et al., 2007), or symptoms of Post-Traumatic Stress Disorder (PTSD) (Kornblith et al., 2003; Shelby, Golden-Kreutz, & Andersen, 2008; Skrzypulec, Tobor, Drosdzol, & Nowosielski, 2009). This dimension may also include changes in priority, fear (Carver et al., 2006; Dow, Ferrell, Haberman, & Eaton, 1999; Mishel et al., 2005; Polinsky, 1994) and positive life changes (Ganz et

al., 2002). Social well-being is related to dealing with relationships, family (Dow et al., 1999; Howard et al., 2007), support (Ashing-Giwa, Tejero, Kim, Padilla, & Hellemann, 2007; Wyatt & Friedman, 1996), and the impact of cancer in how a person relates to society (Carver et al., 2006). The spiritual dimension involves hope (Dow et al., 1999), meaning (Ashing-Giwa & Lim, 2011), religion, belief, and spiritual practices (Ashing-Giwa, Padilla, Tejero, & Kim, 2004; Ganz et al., 2002; Leak, Hu, & King, 2008; Wyatt & Friedman, 1996). These are not independent constructs, changes in one area impact one or more of the other areas so that the construct of HRQOL is a complex balance across different aspects of life (Bloom et al., 2007; Ferrell, Grant, Funk, Otis-Green, & Garcia, 1997).

Ashing-Giwa (2005b) expanded the model of HRQOL previously developed (Ferrans et al., 2005; Wilson & Cleary, 1995) to include context with cultural and socio-ecological variables. Not all researchers use the same naming conventions, for example Zebrack (2000) proposes seven categories of quality of life: "(a) physical concerns (symptoms, pain), (b) functional ability (activity), (C) family well-being, (d) emotional well-being, (e) treatment satisfaction (including financial concerns), (f) sexuality/satisfaction (including body image), and (g) social functioning" (Zebrack, 2000, p. 1397). In this study the Ashing-Giwa (2005b) nomenclature that includes physical, mental, social, and spiritual dimensions is the theoretical map used. Not all instruments use all dimensions and the functioning, cultural, sexual, socioecological dimensions are not often included in instruments (Ashing-Giwa, 2005b, p. 299). In the initial literature review findings fell primarily into the physical, psychological, spiritual and social

domains, with socioeconomic and socio-ecologic findings primarily being related to the social sphere. Impacts on function may be reported in the physical, psychological, or social contexts, and the socioeconomic and socio-ecologic components like age may be reported in the social domain.

HRQOL instruments are designed to capture from the patient "subjective perceptions and assessments of their health" (Wilson, 2004, p. 434). These are not available through objective testing, and patients often perceive different components of the overall conceptual framework as being more important (Wilson, 2004). For example, two women with the same stage and type diagnosis, and with the same treatment regime, may rate their overall health very differently. For a woman who still desires to have children, the impact on her fertility and body image may be of paramount importance, whereas for a woman who is most concerned with her earning potential, how quickly and effectively she can return to work will most likely have the largest impact on her overall perception of her quality of life.

Most researchers at least acknowledged that HRQOL is both subjective and unique to each person. The salience of psychosocial variables changes with age, life stage and for cancer patient's time since diagnosis and treatment. Capturing a person's score on quality of life without capturing the associated salience for that person does not give an accurate picture (Bloom et al., 2007; Zebrack, 2000).

The existential, spiritual and religious aspects of life quality were often not included in older studies although these dimensions are seen in more modern studies by inclusion of instruments built for that purpose, (Zebrack, Ganz, Bernaards, Petersen, &

Abraham, 2006; Zebrack, Yi, Petersen, & Ganz, 2008) or with additions to already existing instruments (Ganz et al., 2002).

Quality of life is a well-documented framework, and many studies have used it as a measure of outcome in breast cancer treatment. Comparing the research on HRQOL is often difficult as a number of standard instruments are used and often as many as four or five different instruments may be used in a study (Bloom et al., 2007; Gotay & Muraoka, 1998; Hewitt et al., 2004; Kornblith et al., 2003; Montazeri, 2008; Zebrack, 2000).

Outcomes measurement and the use of HRQOL is a developing field (Lipscomb et al., 2004a), and researchers often vary in how the variable is constructed, measured, or reported (Zebrack, 2000). As would be expected in relatively broad research area, both sample size and how instruments are used vary considerably across investigations. Some instruments are based on normal populations that are not health impaired. In more recent studies, instruments normed for specific cancer populations like BCS have been developed (Gotay & Muraoka, 1998; Hewitt et al., 2004). There is however an acceptance that HRQOL provides a measure that gives insight into the experience of patients, and their consequent needs for treatment, support and recognition (Lipscomb et al., 2004a)

Overall there are many aspects of breast cancer survival that have been well researched across the total population, including the target population of this review. Long-term impact on a survivor's quality of life (Ganz et al., 2002; Gotay & Muraoka, 1998; Zebrack et al., 2008) is now accepted.

Conceptual definition. HRQOL is a patient reported, subjective assessment or evaluation (Lipscomb et al., 2004a) of the experience and impact of illness on a person (Ashing-Giwa, 2005b). It may or may not have an overall global well-being assessment (Lipscomb et al., 2004a, p. 7). The domains that are of interest in this study are physical, psychological/emotional, economic, spiritual, and social (Ferrans et al., 2005; Ferrans, 2004, p. 15). These domains can often be aggregated to provide an overall score if one is not part of the measure (Powe et al., 2007). HRQOL may change over time (Cella, 1994).

Operational definition. Operationally there are many instruments that measure a component of the concept, and they are sometimes used in concert in a study (Ashing-Giwa, Padilla, Tejero, Kraemer, et al., 2004; Bowen et al., 2007; Ganz et al., 2002). A list of the identified instruments used in HRQOL studies of breast cancer is provided in Chapter 3.

Instruments that measure the concept are often developed for a specific component or purpose in outcomes assessment of health care (Ferrans, 2004). Consequently, researchers may choose different instruments based on their research objectives (Ferrans, 2004), which has the consequence of making comparison across research studies more complex (Lipscomb et al., 2004a). The researcher is often trying to choose an instrument that will be sensitive enough to the particular concerns of the patients and healthcare professionals in a particular combination of site and trajectory point (Ferrans, 2004). For example, the spiritual and family dimension of HRQOL are unlikely to be strong differentiating factors of a drug's efficacy, but are likely to be

important in an end of life inquiry (Ferrans, 2004). The plan in this systematic review was to treat the instruments as moderator variables and compare the effect sizes from different instruments.

HRQOL in Breast Cancer Survival

HRQOL is considered an outcome measure in clinical trials, and breast cancer has received significant focus with of the growing number of survivors who are living longer disease free due to improvements in treatment and detection (American Cancer Society, 2011). A woman's identity is often impacted by the changes in her body from the treatment. This impact may affect family members and her ability to carry out the role she played prior to the cancer (Montazeri, 2008).

In general long- term BCS report quality of life that ranges from satisfactory (Ashing-Giwa et al., 2007; Ashing-Giwa, 1999a) through excellent (Ganz et al., 2002; Giedzinska et al., 2004) with high levels of physical and emotional functioning (Casso et al., 2004; Polinsky, 1994). Their overall functioning was reported as similar to disease free controls (Dorval, Maunsell, Deschênes, Brisson, & Mâsse, 1998; Vinokur, Threatt, Caplan, & Zimmerman, 1989). Von Ah et al. (2012) found no overall differences in well-being between BCS and normal controls, but did identify some areas of difference in detailed analysis. In an earlier review (Russell, Von Ah, Giesler, Storniolo, & Haase, 2008) both African American and white survivors were found to have favorable HRQOL although BCS had a lower sense of overall health than those who had not been diagnosed with breast cancer.

Race

There is considerable diversity in the "Black" population of the United States. Around 16% of the Black population is reported as foreign-born or of foreign-born parentage; those of West Indian heritage account for as much as 10% of the Black population (Williams & Jackson, 2000). These differences in origin are likely to be reflected in beliefs, behavior and culture. Some evidence that "Black" subgroups have different health status was reported. West Indian and Haitian immigrants have lower rates of breast cancer than Black women born in the U.S. (Williams & Jackson, 2000). The use of race in the United States is more closely aligned with social structure than biology (Williams & Jackson, 2000). Researches including African American BCS did not distinguish differences that may have been relevant due to the continuum described above. Responses to research even when the respondents were self-identified as African American possibly come from a spectrum of cultural influence.

Minority subgroups are in positions of cultural, political, and socioeconomic disadvantage (Stratton, Nepaul, & Hynes, 2007). The racial categories in use in the United States are reflections of "differences in power, status and resources" (Williams, 1999, p. 177) and as such may underlie discrimination, and the development of prejudicial attitudes. Race and ethnicity are often confused (Betancourt & López, 1993), or used as interchangeable concepts (Stratton et al., 2007). Racial categories are based on observable characteristics, for example, skin color or geographic location (Betancourt & López, 1993; Stratton et al., 2007). Ethnicity includes assumed commonality based on religious, linguistic, cultural, behavioral or geographic determinants that define a group

of people (Stratton et al., 2007). Hispanic ethnic status is usually recorded separately (Winker, 2004).

A Note on Terminology

Throughout the literature review when quoting from other studies or published material I have, where it matters, maintained the terminology used by the authors of the study. Thus, African American BCS were referred to by some authors as Black, or women of color. European American women were sometimes referred to as Caucasian, or Non-Hispanic White, or White, or varying forms of these. Otherwise, the terminology of this discussion refers to African American women and European American women.

BCS and Race

The number of minority women in the population of BCS is increasing. African American women are more often diagnosed with breast cancer than any other cancer (Mishel et al., 2005). They are more likely to have been diagnosed with advanced states of breast cancer, and their survival chances are smaller than European American women (American Cancer Society, 2011; Li & Malone, 2003; Northouse et al., 1999). The difference in mortality rates persist even adjusting for hormone receptor status and staging (Li & Malone, 2003). African American BCS have also been more likely to have more aggressive surgical treatment (mastectomy versus lumpectomy) than European American women although at least one study found exactly the opposite (Bradley, Given, & Roberts, 2002). Differences in mortality are not explained by primary treatment (Li & Malone, 2003). The availability of tamoxifen and other subsequent drugs that are used in hormone receptor positive breast cancer is thought likely to have had a significant

contribution to the reduction in the mortality rate for European American women. African American women are less likely to have a receptor positive breast cancer, and by 2007 the mortality rate was "41% higher in African American women than white women" (American Cancer Society, 2011, p. 10).

The differences seen in incidence and treatment between different ethnic groups extend to HRQOL (Giedzinska et al., 2004; Paskett et al., 2008). There are disparities between African American and European American BCS that include their coping strategies, how they were treated, and the impact it has on their lives (Ashing-Giwa, Padilla, Tejero, Kraemer, et al., 2004). As well as differences in physical functioning (Bowen et al., 2007; Deimling, Schaefer, Kahana, Bowman, & Reardon, 2003; Paskett et al., 2008) there may be different predictors of physical and emotional functioning (Ashing-Giwa et al., 2007; Bowen et al., 2007; Giedzinska et al., 2004) and differences in social functioning (Bourjolly, Kerson, & Nuamah, 1999).

Studies focusing on the survival experience of minority women have been published, with some focused on late effects (Ganz et al., 2002; Mishel et al., 2005; Northouse et al., 1999; Paskett et al., 2008; Powe et al., 2007; Russell et al., 2008; Von Ah et al., 2012). However, much research was focused on European American (Giedzinska et al., 2004; Von Ah et al., 2012) women. Even when African American women were targeted, the research may have limited ability to generalize the findings because of the small sample sizes (Paskett et al., 2008), and because the studies don't always include a normal comparison (Von Ah et al., 2012). Race has been used as a proxy for variables that may be more salient contributors to the measures in cancer

quality of life research; for example, type and intensity of treatment, socio-economic status, cultural variables, and attitudes towards cancer and health in general (Ashing-Giwa et al., 2007; Giedzinska et al., 2004).

Ashing-Giwa and Ganz (1997) executed a qualitative study of African American women and breast cancer. The study was in response to their observation that the numbers of minority women included in breast cancer survival studies was too small to be able to draw conclusions. The study was conducted in three phases using experts in key informant interviews (*n*=12), small focus groups (*n*=23) and in-depth interviews of (*n*=8) women selected from a different quality of life study (Ashing-Giwa & Ganz, 1997, pp. 22–23). Some of the issues that emerged from this study were particularly relevant to the phase of the cancer trajectory focused on diagnosis and treatment. These issues included knowledge about breast cancer, and the patient physician relationships (Ashing-Giwa & Ganz, 1997, p. 32). Other issues were relevant throughout the trajectory. SES was seen as a key component of quality of life and psycho-social issues, with the authors commenting that "ethnicity and poverty influence women's experiences with chronic illness such as cancer"(Ashing-Giwa & Ganz, 1997, p. 34). In addition, Ashing- Giwa and Ganz (1997, p.33) found that there was a perceived lack of social support, and an interaction with the socialization of African American women that teaches that they must be strong and independent. The researchers found that the strong spirituality of the participants molded both their belief and coping systems (Ashing-Giwa & Ganz, 1997, p. 25).

Bradley et al. (2002, p. 490) reported “race was not statistically significantly associated with unfavorable breast cancer outcomes.” Analyzing data collected from 1996-7 study of a cohort from a single metropolitan center, the researchers found that “socioeconomic status was associated with late-stage at diagnosis, treatment received and death” (Bradley et al., 2002, p. 490). In this study, the categorization by race was only into either White (81%) or African American (19%), and the African American women were less likely to receive adjuvant radiation, less likely to receive surgery and more likely to have died from cancer.

Bradley et al., (2002) also noted that when data were adjusted for income, the effect of race diagnostic stage was “greatly reduced” (Bradley et al., 2002, p. 490). Both lower economic conditions and lack of health insurance were associated with lower survival. A woman who lives in a lower income area has a lower five-year survival rate than women who live in a high income area regardless of the stage of cancer diagnosis (American Cancer Society, 2011). Bradley et al., (2002, p. 493) found that "Controlled for age, race, marital status, cancer stage, Medicaid status, and census tract poverty level” stage at diagnosis and rate of death did not show a significant difference between African American and European American women. In this study, 13% of white women were considered to live within high poverty areas, and 84% of African American women lived within high poverty areas (Bradley et al., 2002, p. 495).

Small differences that were termed “clinically meaningful” (Paskett et al., 2008, p. 3223) in overall general health were found between African American and European American BCS (Paskett et al., 2008; Ye, Shim, Garrett, & Daniels, 2012) although some

studies found no significant differences (Carver et al., 2006; Casso et al., 2004). African American BCS had lower general health assessment that African American women who had not been diagnosed (Paskett et al., 2008). A finding that was consistent with African Americans in the general cancer survivorship population (Powe et al., 2007), but inconsistent with an earlier finding that African American BCS, who were 3 years from diagnosis had a higher HRQOL than age matched women who had not had breast cancer (Northouse et al., 1999). European American BCS also had lower general health assessments than European American women who did not have cancer, although these too were small distinctions (Paskett et al., 2008).

Age in Breast Cancer

Increasing age in BCS tended to coexist with more comorbid conditions which impacted the physical dimension of HRQOL even while better mental health and wellbeing were reported (Vinokur et al., 1989). Cimprich, Ronis, & Martinez-Ramos (2002) in a study of 105 long-term BCS using the Quality of Life-Cancer Survivor (QOL-CS) instrument found that age at diagnosis was a key influencer of HRQOL. Giedzinska et al., (2004) in a larger more ethnically diverse study of 621 BCS who were within 5 years of diagnosis, including African Americans, European Americans, Latinas and Asian Americans, reported that age and income were predictors of overall HRQOL for both African American and European American BCS. In African American survivors they were also predictive of worse physical well-being (Giedzinska et al., 2004).

In their study of 215 relatively young (40-49 year olds) who were between 5 and 10 years from diagnosis Casso et al.(2004) found that younger BCS report HRQOL that

was like women who were never diagnosed with breast cancer. They do report that there was an indication of lower emotional well–being in younger women (Casso et al., 2004), a finding that was echoed in other studies (Ganz et al., 2002; Vinokur et al., 1989).

At the highest level differences between African American and European American women BCS were small if identified at all, and were more likely associated with differences in socioeconomic variables than ethnic or racial ones.

Dimensions of HRQOL

HRQOL varies across the cancer trajectory, individually, and, in populations, when trends across survivors were examined (Chopra & Kamal, 2012). Investigators generally agreed that proximity in time to the diagnosis will negatively impact HRQOL (Ellman & Thomas, 1995; Holzner et al., 2001; Vinokur et al., 1989). Holzner et al. (2001) reported that 5 years post diagnosis there was a decrease in HRQOL, but Casso et al., (2004) found no link between proximity to diagnosis and decrease in HRQOL

Many authors in this area have mentioned the importance of not only looking at overall HRQOL but also of understanding how the underlying domains are distinguished (Avis et al., 2006; Cella et al., 1993; Osoba et al., 1997; Ringdal & Ringdal, 1993; Schag et al., 1991). Wherever possible, in this analysis, the studies were examined at the lower level of physical, psychological, social and spiritual domains.

Physical Dimension

The physical and physical functioning components (Ashing-Giwa, 2005b) of the breast cancer survival trajectory change after diagnosis and treatment, but remain a potent component of long-term survival. An example of this is the growing awareness of heart

attack risk for women who had undergone adjuvant treatment (Darby et al., 2013). This area of HRQOL includes physical concerns resulting from disease and treatment, including symptoms (Dow et al., 1999; Polinsky, 1994), pain, fatigue (Ashing-Giwa, Padilla, Tejero, & Kim, 2004), perceived, and observed bodily functions, or upset of the functions (Powe et al., 2007, p. 436). Additionally the ability to function in a normal way (Ashing-Giwa, 2005b) is considered as part of the physical domain.

Physical issues in breast cancer persist for long-term survivors and impact their measured HRQOL (Ashing-Giwa, 1999a; Ashing-Giwa, Padilla, Tejero, Kraemer, et al., 2004; Dorval et al., 1998; Polinsky, 1994). At least one study reviewed did not find physical issues to be a strong component of HRQOL impact (Wyatt & Friedman, 1996) possibly because the population being studied was of a broader cancer population rather than only restricted to BCS. Cardiotoxicity and other late treatment sequelae (Carver et al., 2006), and general long-term physical impairments (Russell et al., 2008) are reported in the research, with impact on HRQOL. Surgical arm lymphedema is reported in a significant minority of BCS (Beaulac, McNair, Scott, LaMorte, & Kavanah, 2002; Dorval et al., 1998; Kornblith et al., 2003; S. H. Lee, Min, Park, & Jung, 2012). Numbness at the surgical site that may be related to adjuvant therapy was also reported and impacts measures of HRQOL (Kornblith et al., 2003; Polinsky, 1994).

Post treatment fatigue and pain (Dow et al., 1999) can be ongoing for many years (Ashing-Giwa, 1999a; Carver et al., 2006; Chopra & Kamal, 2012; Polinsky, 1994). The impact on HRQOL was seen to be reduced in those BCS who had a domestic partner (Carver et al., 2006; Ganz et al., 2002; Helgeson & Tomich, 2005), and mitigated by

higher levels of education in BCS (Carver et al., 2006). Von Ah et al. (2012) found fatigue to be the strongest predictor of overall HRQOL in their study of 62 long-term African American BCS compared to 78 normal controls.

Reported fatigue impacts HRQOL (Northouse et al., 1999) and African American BCS report more fatigue than other survivors (Leak et al., 2008; Von Ah et al., 2012). They also report more impact from hot flashes (Von Ah et al., 2012), and more pain than African Americans without a breast cancer diagnosis (Leak et al., 2008; Paskett et al., 2008), both of which lower reported HRQOL. Sleep issues (Dow et al., 1999; Northouse et al., 1999), breast related symptoms that persist into survival (Casso et al., 2004), and general distress over symptoms (Northouse et al., 1999) that may impact a woman's ability to function in what she considers a normal way (Russell et al., 2008), were identified as having impacts on HRQOL.

While all physical components might be seen as sequelae of disease and treatment, there were some associations that were clearly drawn in the research. BCS were found to have more comorbid conditions and take more medications, both of which were associated with lower HRQOL (Vinokur et al., 1989). While this review was restricted to early-stage breast cancer, Vinokur et al. (1989) also found that the severity of the diagnosis a woman was given impacts negatively on HRQOL. Only a few studies reviewed found that mastectomy had a negative impact on HRQOL (Casso et al., 2004; Skrzypulec et al., 2009). In a large study of 763 disease free BCS, an average of 6.3 years post treatment, Ganz et al. (2002) found no correlation between type of surgery and HRQOL.

Adjuvant therapy, which includes chemotherapy and hormonal therapy including tamoxifen, aromatase inhibitors and drugs that impact hormone balance, has significant long-term effects (Casso et al., 2004) on women and their reporting of HRQOL (Ganz et al., 2002). The impact was not only seen in physical functioning (Ahles et al., 2005; Ganz et al., 2002) but also in general health perceptions (Ganz et al., 2002) and overall symptom distress (Giedzinska et al., 2004). Bowen et al. (2007) found a strong association between adjuvant therapy and fatigue and depression and associations have also been shown with lower social and psychological components of HRQOL (Carver et al., 2006; Casso et al., 2004).

Race has an impact in the physical dimension of well-being (Russell et al., 2008). However, while both African American and European American BCS reported more physical symptoms than women who had not had breast cancer, according to Von Ah et al. (2012), there was no difference in their reported ability to function on a physical level. Giedzinska et al. (2004) found worse functioning for African American BCS and Paskett et al., (2008) found that both African American and European American BCS had lower physical functioning than non-BCS, although the effect was small. Overall African American BCS had a worse physical HRQOL than European American BCS (Giedzinska et al., 2004) at a small but clinically useful level (Paskett et al., 2008). African American BCS reported slightly higher physical limitations on their ability to perform normally in their role (Paskett et al., 2008; Russell et al., 2008). Both African American and European American BCS reported a slightly lower level of vitality than women who had never been diagnosed (Paskett et al., 2008). African American BCS reported more sleep

disturbance that African American women who had no breast cancer diagnosis (Leak et al., 2008; Paskett et al., 2008; Von Ah et al., 2012) and poorer HRQOL (Von Ah et al., 2012).

Older BCS (>65 years of age) tended to have worse physical HRQOL (Cimprich et al., 2002), have more comorbid disease (Sammarco, 2003), and experience more physical difficulties (Vinokur et al., 1989). In African American survivors no relationship was found between overall HRQOL and age at diagnosis (Leak et al., 2008).

The timing of physical issues has an impact on HRQOL. During treatment physical problems often have a patient's attention (Northouse et al., 1999) but the development of morbidity later in the trajectory was linked to poorer HRQOL as well (Rietman et al., 2003). The impact of these late effects is important in evaluating the full impact of cancer treatment (Mols, Vingerhoets, Coebergh, & van de Poll-Franse, 2005).

Psychological, Emotional, Mental Dimension

Ashing-Giwa, Padilla, Tejero, and Kim (2004) defined this dimension in the following way "Psychological functioning is measured by the presence or absence, as well as levels, of depression, anxiety, and general emotional well-being" (p. 451). Included in this dimension are impacts like mood swings, fear, distress from various causes, and body image issues. This dimension also includes both positive and negative aspects of the experience (Powe et al., 2007, p. 436).

Long-term BCS may suffer psychosocial distress (Russell et al., 2008), with more psychological issues and HRQOL deficits seen the psychological functioning component of their profile (Ashing-Giwa, 1999a; Meyer & Aspegren, 1989; Russell et al., 2008). On

the positive side, some BCS report a deeper maturity that translates into an improved HRQOL (Halttunen, Hietanen, Jallinoja, & Lönnqvist, 1992)

Ahles et al. (2005) found no association with having had adjuvant therapy and the psychological component of HRQOL, but cognitive impairment has been shown with adjuvant therapies in long-term BCS (Brezden, Phillips, Abdolell, Bunston, & Tannock, 2000; Carver et al., 2006; Phillips & Bernhard, 2003; Russell et al., 2008). Association between breast conserving surgery and reduced psychological HRQOL was not found (Meyer & Aspegren, 1989; Omne-Pontén, Holmberg, & Sjödén, 1994).

Depression and anxiety were negatively associated with HRQOL in breast cancer patients during treatment (Longman, Braden, & Mishel, 1999). Both depression and anxiety have been associated with lower HRQOL in long-term BCS (Ashing-Giwa & Lim, 2011; Tomich & Helgeson, 2002; Weitzner, Meyers, Stuebing, & Saleeba, 1997). Perkins et al. (2007) found better psychological resources were correlated with lower levels of depression and better general health perception as well as improved HRQOL. Ellman & Thomas (1995) in a study of 290 matched pairs of BCS between 50 and 78 years old found less anxiety and depression in BCS than in controls. However, Weitzner et al. (1997) in a smaller study of BCS (n=60) versus a breast screening group (n=93) found higher incidence of mild to moderate depression symptoms and trait anxiety in the BCS group, with a lower HRQOL for those women with depression scores in the symptomatic range.

African-American survivors were less depressed, and displayed less anxiety than European American survivors and were less likely to have worries about cancer

(Deimling et al., 2006). African-American survivors, according to Deimling et al. (2003), experience less psychosocial impact than European American BCS. The explanation for this was “it is possible that this and other cultural groups express their distress differently and that the distress measures used in this study do not capture the nature of their distress" (Deimling et al., 2006, p. 157).

Post-Traumatic Stress Disorder symptoms were identified in a small number of long-term BCS with an impact on HRQOL (Kornblith et al., 2003; Skrzypulec et al., 2009). Long-term survivors, with emotional distress and PTSD symptoms, demonstrated lower HRQOL that was mainly associated with chemotherapy and a later stage diagnosis (Amir & Ramati, 2002). Emotional impacts of breast cancer were found to stabilize for most BCS after about two years (Ashing-Giwa & Lim, 2011; Neyt & Albrecht, 2006). Some emotional issues continue long-term (Ashing-Giwa & Lim, 2011) with the level of impact being reduced and less negative thoughts reported by women with partners (Carver et al., 2006; Ganz et al., 2002; Helgeson, Snyder, & Seltman, 2004).

"Years later, concerns about recurrence are likely to be most prominent along with the distress associated with continued monitoring and testing (Deimling et al., 2006, p. 144).” Worries about the future and recurrence continue for BCS into long-term survival (Halttunen et al., 1992; Meyer & Aspegren, 1989). Medical checkups and mammograms make the worries prominent (Polinsky, 1994), often bringing concerns about another cancer (Deimling et al., 2006), or uncertainty about the future (Dow et al., 1999; Mishel et al., 2005) into immediate attention. African American BCS reported fears of recurrence that impact HRQOL (Northouse et al., 1999).

The strongest associations with poor HRQOL in the area of body image and appearance issues were medical variables (Carver et al., 2006). A mastectomy (Giedzinska et al., 2004; Omne-Pontén et al., 1994), a chemotherapy regime (Carver et al., 2006), a younger age at diagnosis, and having a lower income (Giedzinska et al., 2004) meant a survivor was more likely to report body image issues. Being a BCS was enough to have a higher risk of body image problems (Ashing-Giwa, Padilla, Tejero, Kraemer, et al., 2004; Carver et al., 2006). African American women report more body image issues, but when demographic and medical variables were controlled this difference becomes insignificant (Giedzinska et al., 2004).

Racial identification predicts "psychological distress, anxiety, depression and cancer related worries, with African-Americans exhibiting lower levels of distress than whites" (Deimling et al., 2006, p. 143). African American BCS reported more optimistic outlook (Northouse et al., 1999) and more positive mental health impact (Ganz et al., 2002).

Older BCS suffer more depression (Perkins et al., 2007) and a negative correlation between their level of perceived uncertainty and their reported HRQOL (Sammarco, 2003).

Social and Socioeconomic Dimension

The social dimension focusses on engagement in social activities (Ashing-Giwa, Padilla, Tejero, & Kim, 2004). It includes support, leisure activities, family, and sexuality (Powe et al., 2007). Functional well-being is also gauged by the ability to engage in self-care and perform family and work responsibilities (Ashing-Giwa, Padilla,

Tejero, & Kim, 2004), the ability to perform tasks, work towards goals, or perform social roles (Powe et al., 2007).

Typically SES is used as an explanatory variable in health research, or it is used as a control for other health correlates (Oakes & Rossi, 2003). Krieger et al. (1997) identify two major components - economic indicators and indicators that were more related to social position. Overall these indicators were considered to be a measure of the ability to access resources or the prestige and social power that an individual can command (Braveman et al., 2005). Measures associated with resources include income, wealth, education or the inadequate resources associated with poverty, whereas prestige based measures were associated with rank or status in the social hierarchy (Krieger et al., 1997). SES is related to the social dimension of HRQOL (Ferrans, 2004).

Different measures of SES may have different meanings for different groups in the population (Braveman et al., 2005). Minorities including racial/ethnic groups, women and older populations who do not participate in the regular economy or who may be paid less than a white male for the same work may be categorized incorrectly (Berkman & Macintyre, 1997). The age of the cohort under investigation can change the impact of different educational levels. Not as many people went to college in the earlier part of the twentieth century as did in the 1990s, so the level of education attained has a different meaning for different age cohorts (Braveman et al., 2005). Thus, considerations in the measurement of SES require that care is taken in any interpretations of association between SES and HRQOL, especially where the group under consideration is female, minority and older.

There is not a straight-line relationship between changes in SES and health status (Daly et al., 2002). Depending on the measure used for SES and the component of health being measured the relationship changes across social groups (Abramson, Gofin, Habib, Pridan, & Gofin, 1982; Braveman et al., 2005; Daly et al., 2002). The level used to measure health, for example, symptoms rather than overall diagnosis can change the pattern of relationships between SES and health (Betancourt & López, 1993) as can the time in when SES is measured (Krieger et al., 1997).

There is a significant body of knowledge that supports the interaction between race and SES in correlations with health. Differences in race often become apparent where SES is considered "equivalent" (Williams, 1999). Williams (1999) suggests that while SES does account for much of the racial difference in health status, at every level of SES, African Americans, and other minority group members, have lower life expectancy that their white counterparts (Williams, 1999). The same levels of income across racial/ethnic groups don't mean the same access to resources. If wealth rather than income is measured the levels were different for minorities and whites and even when income health insurance and clinical status were held constant, the white population is likely to get better treatment (Williams, 1999). Bias in medical care (Williams, 1999) is observed in the differences in care received by minority groups, and in access to health care (Williams, Lavizzo-Mourey, & Warren, 1994; Winker, 2004). SES may measure different concepts in different cultures, ethnic and demographic groups (Berkman & Macintyre, 1997).

Ye, Shim, Garrett, & Daniels (2012) found "race had a significant impact on quality of life for all the cancer patients" (p. 302). For breast cancer patients the relationship was not as clear, and reports were more likely to associate ethnic minority status with other socioeconomic characteristics when discussing the impact on overall HRQOL (Ashing-Giwa et al., 2007; Giedzinska et al., 2004). In their multi-ethnic sample, Ashing-Giwa et al., (2007) noted that both African Americans and European Americans had a favorable SES. They proposed that there may be a more diversified impact on overall HRQOL in a population sample that had a more diversified SES profile. In an early study, Ashing-Giwa (1999a), reported no link between racial categorization and overall HRQOL.

Family distress (Dow, Ferrell, Leigh, Ly, & Gulasekaram, 1996), while reported as less of an issue if the patient has a partner (Ganz et al., 2002; Helgeson et al., 2004), was none the less still an issue for BCS in the social domain of HRQOL. Worries about the burden on the family from the impact of breast cancer were reported (Ashing-Giwa, Padilla, Tejero, Kraemer, et al., 2004; Carver et al., 2006; Dow et al., 1996). Having higher education was associated with less distress about the family, and lower scores on psychological variables indicated more concerns about the family (Carver et al., 2006). Marital adjustment issues (Meyer & Aspegren, 1989) and a feeling of lack of social support (Moore, 2001, p. 200; Wyatt & Friedman, 1996) both were associated with a lower HRQOL in the social domain. Other factors that were associated with lower HRQOL in the social domain included chemotherapy (Ahles et al., 2005) and lower scores on psychological variables (Carver et al., 2006).

Sexual issues were more often reported in BCS (Chopra & Kamal, 2012; Dorval et al., 1998; Ganz et al., 2002; Kornblith et al., 2003). There is often a physical and psychological component as well as social dysfunction in sexual health assessments. General concerns with sexuality (Dow et al., 1999; Ganz et al., 2002), acknowledged sexual problems (Ashing-Giwa, 1999a; Ashing-Giwa, Padilla, Tejero, Kraemer, et al., 2004; Carver et al., 2006; Chopra & Kamal, 2012; Kornblith et al., 2003), and issues with sexual satisfaction (Dorval et al., 1998) were reported as impacting HRQOL. Casso et al. (2004) identified a mild impairment using the sexual scale of the CARES (Cancer Rehabilitation Evaluation System) instrument. In at least one study, psychological variables more consistently impacted the measures of sexual disruption than physical issues (Carver et al., 2006). African American BCS report less sexual issues than European American BCS (Giedzinska et al., 2004).

Financial issues while less for those with higher educational attainment (Carver et al., 2006; Kornblith et al., 2003) were reported by some BCS. Some report difficulties in functioning financially (Helgeson et al., 2004), some report concerns about health insurance coverage in the future (Ashing-Giwa, Padilla, Tejero, Kraemer, et al., 2004; Polinsky, 1994). Carver et al. (2006) found that medical variables like cancer stage and treatment were correlated with financial concerns, although chemotherapy was not associated with a lower social domain score (Ahles et al., 2005).

Lower SES was associated with poorer HRQOL, especially in the area of emotional health (Ashing-Giwa & Lim, 2011; Hewitt et al., 2004). Lower income had a negative impact on HRQOL (Casso et al., 2004) and emotional health (Ashing-Giwa &

Lim, 2011) as did lower levels of education and being a non-English speaker (Ashing-Giwa & Lim, 2011). A higher level of attained education was associated with better HRQOL (Carver et al., 2006). A lower level of attained education was associated with a lower HRQOL (Northouse et al., 1999) for African American BCS.

For both African American and European American women social support was influential in HRQOL (Ashing-Giwa et al., 2007; Northouse et al., 1999). African American BCS report higher levels of social support than normal controls (Von Ah et al., 2012), and higher levels than European American BCS (Giedzinska et al., 2004). African American BCS report feeling support from their family (Howard et al., 2007) but a lower level of family well- being (Von Ah et al., 2012).

While lower life stress had a positive effect on HRQOL for African American BCS (Ashing-Giwa et al., 2007), many African American BCS report life stress as a significant issue (Russell et al., 2008). Psychosocial functioning varies in African American BCS (Russell et al., 2008) but even after controlling for demographics and comorbidities social functioning was lower for African American BCS (Ye et al., 2012).

There was a positive relationship with HRQOL and a perception of better social support for older BCS (Sammarco, 2003). Younger (<44 years) BCS showed both more social issues (Casso et al., 2004) and worse social HRQOL (Cimprich et al., 2002).

Spiritual

Spirituality, independent of religion, is concerned with the way people find meaning and purpose in their lives and perhaps death. It does not necessarily require belief in a higher power, or an organized religious group although it is possible for

spirituality to manifest in that way (Davison & Jhangri, 2010). In the Ashing-Giwa (2005b) model both the spiritual and existential components of experience are included in this dimension.

Studies have provided insight into the positive nature of changes that impact the spiritual dimension of HRQOL. Increased hope, better defined life purpose and positive emotional changes (Dow et al., 1996) were noted in long-term BCS. Long-term BCS also reported positive spiritual growth (Ganz et al., 2002) positive emotional outcomes, an optimistic change in outlook and finding meaning in life (Ashing-Giwa & Lim, 2011; Bower et al., 2005; Meyerowitz et al., 2008).

While spirituality was not included in all studies, when it was, African American women assessed that higher HRQOL was a reflection and response to their spiritual beliefs (Chopra & Kamal, 2012). Several studies have linked coping and spirituality for African American BCS (Russell et al., 2008). They reported higher levels of spirituality (Ashing-Giwa et al., 2004) that supports their ability to cope with the sequelae of breast cancer (Von Ah et al., 2012). In a comparison of African American BCS and those who have not had the disease, Von Ah et al. (2012) found that spirituality was high in all African American women in their sample, and found no difference in spirituality amongst either the BCS or non-BCS groups of either racial categorization

African American women tend to report a religion based spirituality (Ashing-Giwa, Padilla, Tejero, Kraemer, et al., 2004) and increasing levels of spirituality were associated with higher HRQOL (Leak et al., 2008). European American women may report other forms of spiritual practice or belief not associated with religiosity (Ashing-

Giwa, Padilla, Tejero, Kraemer, et al., 2004). African American BCS report more positive growth and appreciation for life (Von Ah et al., 2012), and they report more found meaning in the cancer experience than European Americans (Giedzinska et al., 2004; Von Ah et al., 2012).

Systematic Reviews

Several terms are used relatively interchangeably in the literature to refer to the process of attempting to integrate primary research to create a generalized view of a body of knowledge. Research synthesis, research review and systematic review have slightly different connotations (Cooper et al., 2009, p. 6). Meta-analysis can be used to refer to the whole process or to "A statistical analysis of results from separate studies, examining sources of differences in results among studies, and leading to a quantitative summary of the results if the results are judged sufficiently similar to support such synthesis" (Porta, 2008, p. 154). Lipsey & Wilson (2001) explain that this form of analysis is another approach to survey research except that the research reports are surveyed rather than people. In its purest form meta-analysis is distinguished from the traditional "narrative review" reports of synthesized primary research, by bringing the same rigorous methodological approaches that are required from experimental research (DeCoster, 2004).

Following the example of Chalmers (2007) and the Dictionary of Epidemiology (Porta, 2008) this study referred to the overall process of defining the problem, collecting the research evidence, selecting and coding the studies, analyzing and integrating the evidence, interpreting the cumulative evidence and presenting the results (Cooper et al.,

2009) as a systematic review and the included process of statistical integration and summary as meta-analysis (Borenstein et al., 2009; Cooper et al., 2009).

Some authors (DeCoster, 2004; Lipsey & Wilson, 2001) refer to the whole process as meta-analysis. The distinction that the systematic review is designed to "limit bias in the assembly, critical appraisal, and synthesis of all relevant studies on a specific topic" (Porta, 2008) is an important aspect of the newer use of the terminology that is reflective of the rigorous process that has developed with the increasing attention to the value of the synthesis of prior studies (Chalmers, 2007; Cooper et al., 2009).

Rationale for Consolidating and Integrating Research

Chalmers's (2007) eloquent exposition of the value of the systematic review is summarized in the following: "those who say that systematic review and meta-analyses are not 'proper research' are wrong: it is clinical trials done in the absence of such reviews and meta-analyses that are improper scientifically and ethically" (Chalmers, 2007, p. 53).

Chalmers (2007) reasons to conduct reviews included developing an understanding of the state of knowledge in a specific area, potential research avenues (Borenstein et al., 2009; Chalmers, 2007; Cooper et al., 2009), and the earlier detection of an effect. He uses the example of Sudden Infant Death Syndrome (SIDS), where the knowledge existed in the effects found in research studies of back sleeping 15 years before it was found in the early 1990s. If a review had been done many lives would have been saved (Chalmers, 2007, pp. 46–47). Chalmers (2007) identified that evaluation of planned research for potential value prior to incurring the costs of the projects, in for

example, large drug trials (pp. 43–46), and the possibility of providing information that is more tailored to the needs of clinicians and patients by examining relevant research, rather funding and conducting undirected research studies (pp. 49–52) were benefits of meta-analysis in a purely practical perspective.

This study was planned consolidate data from quantitative studies (Randolph, 2009) and provide an understanding not only of the direction of the effect seen but an estimation of its size (Ellis, 2010). While there have been a significant number of studies done in the general area of long-term survival from breast cancer, many of them focused on a literature review rather than including meta-analysis. The question is complex, with multiple contributing factors. Many of the studies focus on different aspects of the HRQOL construct but do not operationally define their variables the same way. Significantly while some researchers have included the dimension of race in their work (Ashing-Giwa, Tejero, Kim, Padilla, & Hellemann, 2007; Ashing-Giwa, Padilla, Tejero, & Kim, 2004; Ashing-Giwa et al., 2010; Aziz & Rowland, 2002; Betancourt & López, 1993; Bradley, Given, & Roberts, 2002; Buki et al., 2008; Eversley et al., 2005; Freedman et al., 2011; Giedzinska, et al., 2004; Gordon, 2003; Newman et al., 2002), many have not reported on this variable in their results.

Several studies have integrated parts of the considerable body of knowledge related to breast cancer survivorship. Hewitt, Herdman, & Holland (2004b) surveyed the interventions for psychosocial needs of BCS. Several meta-analyses have been produced focused on the issues of survivorship in cancer generally, including quality of life for African American cancer survivors (Powe et al., 2007), the link between cancer survival

and being unemployed (de Boer, Taskila, Ojajärvi, van Dijk, & Verbeek, 2009) and the effects of psychosocial interventions on survival time (Chow, Tsao, & Harth, 2004). In breast cancer specifically meta-analyses have been published on impacts of hormone replacement therapy (Meurer & Lena, 2002), pregnancy following breast cancer diagnosis (Azim et al., 2011), how psychosocial factors may influence the development of breast cancer (McKenna, Zevon, Corn, & Rounds, 1999), the impact of exercise (McNeely et al., 2006), mortality and SES in African American BCS (Newman et al., 2002), and the effect of radiation on early-stage breast cancer (Reynolds, 2006). The use of meta-analysis has tended to be more for the understanding of treatment associated effects, while the narrative review was used more for psychosocial questions including reviews that support the development of research agendas for specific groups (Berger, 2011; Girgis & Butow, 2009).

The use of meta-analysis in this area of research allows for an understanding of the size of the effect seen across dimensions of the HRQOL construct (Ellis, 2010), and it was planned to determine if an impact from the type of instruments used to collect data (Borenstein et al., 2009; Lipsey & Wilson, 2001)could be observed. The coding process as well as the statistical analysis was planned to allow for an assessment of the gaps in the current body of research (Ellis, 2010), and was expected to provide support of an assessment of the kinds of interventions most likely to be needed. The use of this methodology was chosen to inform and support further understanding and research in this area.

The Process of the Systematic Review

The systematic review including meta-analysis provides a set of procedures to "systematically review the research examining a particular effect" (Ellis, 2010, p. 95) from a set of previously conducted research projects (Chalmers, Hedges, & Cooper, 2002; Chalmers, 2007; Cooper et al., 2009). In the social sciences, large scale randomly controlled trials that may provide definitive answers are rare (Ellis, 2010), rather understanding advances in small often contradictory steps, and achieving a clear picture of the state of knowledge requires a concerted effort to review and consolidate data from many different research studies (Ellis, 2010; Lipsey & Wilson, 2001). Meta- analysis allows contradictory results in research using different statistics to be combined and the overall trend and size of the effect identified (Borenstein et al., 2009; Cooper et al., 2009; Ellis, 2010). Meta-analysis also allows for an understanding of the impact of variables in the research that impact the result (Ellis, 2010; Lipsey & Wilson, 2001).

There has been a growth in the number of systematic reviews, research reviews, research synthesis and meta-analysis studies, and in the percentage of citations that are associated with those methodologies. In the Science Citation Index Expanded and the Social Sciences Citation Index there was a growth from less than 1000 citations per year in 1995 to more than 3500 or more than 25% of citations in 2005 (Cooper et al., 2009, p. 10). There was a sometimes passionate championing (Chalmers, 2007) of the cause of consolidating research, even gold standard research like randomized controlled trials in medical research as a precursor to further investigation.

Systematic review including meta-analysis has some significant advantages when trying to synthesize and consolidate data across a significant body of work. As a structured technique, it requires the documentation of the process used so that theoretically another researcher could take the same body of work and reach the same conclusions (Lipsey & Wilson, 2001; Randolph, 2009). The use of the effect- sizes means that a more nuanced synthesis is possible with the ability to test findings that differ across research reports (Borenstein et al., 2009; Cooper et al., 2009; Ellis, 2010; Lipsey & Wilson, 2001). Using meta-analysis may allow relationships across studies that would not appear in a narrative approach and by using the systematic coding and management approach of meta-analysis the inclusion of a large number of studies is possible (Lipsey & Wilson, 2001).

A meta-analytic review includes articles based on more than the author's subjective thinking because the search and inclusion criteria are publicly shared as part of the process of the study (DeCoster, 2004). The subjectivity of the author can mean that the conclusions of one reviewer can vary significantly from another on the same body of work (Randolph, 2009). Narrative reviews, when comparing results are dependent on statistical significance for evaluation and are at the mercy of sample size much more than the meta-analytic approach (DeCoster, 2004; Randolph, 2009). There is little option in the narrative review in being able to reach conclusions about how differences in methodology influence the outcome or any provision of the classification rules for methodological differences (DeCoster, 2004; Jacobsen, 2009).

The systematic review is not perfect and has some significant criticisms that are leveled against the process. Not the least of these criticisms include the amount of effort involved (Lipsey & Wilson, 2001), and the challenge that the process is mechanistic (Lipsey & Wilson, 2001). The impact of publication bias and lack of objectivity on the part of the researcher must be considered when attempting a meta-analysis (Cooper et al., 2009; DeCoster, 2004; Ellis, 2010; Lipsey & Wilson, 2001). The increasing use of the methodology of the systematic review (Chalmers, 2007; Cooper et al., 2009) has led to refinements and improvements in technique (Chalmers et al., 2002) that are focused on making the process transparent while acknowledging that there are subjective components to the execution of the process (Borenstein et al., 2009).

Using this methodology is neither a quick nor easy approach to integrating data (Lipsey & Wilson, 2001). The process is labor intensive in developing and documenting the search and inclusion criteria, in acquiring both published and unpublished studies, developing the coding schema, reading and coding the studies, developing the database to hold the information, acquiring the specialized statistical knowledge to select and execute the appropriate effect sizes and finally interpreting and publishing the outcome (DeCoster, 2004; Lipsey & Wilson, 2001).

The criticism that this approach is mechanistic is not necessarily a negative when viewed in the light of research rigor (Lipsey & Wilson, 2001; Randolph, 2009). However, the associated charge that this approach to the data may lead to a lack of sensitivity to important issues is valid (Lipsey & Wilson, 2001). The use of the coding approach of meta-analysis is analogous to the use of a survey questionnaire that uses

closed ended questions (Lipsey & Wilson, 2001). Slavin (1995) in his approach of "best evidence" synthesis suggests a combination of meta-analytic and qualitative review so that key issues that are not visible in the meta-analysis can nevertheless be made visible as part of the interpretation of the data (Randolph, 2009). The systematic review and meta-analysis should be considered as a "shared subjectivity" rather than an "objective" methodology (DeCoster, 2004, p. 4). It is the overt documentation of the "subjective decisions" that is one of the key strength of meta-analysis as an approach (DeCoster, 2004; Lipsey & Wilson, 2001).

As one increases the breadth of the area of knowledge under consideration, there is an increasing criticism that meta-analysis tries to "add together apples and oranges" (DeCoster, 2004, p. 3). Overgeneralization can occur in meta-analysis just as it can occur in a narrative review (DeCoster, 2004; Lipsey & Wilson, 2001). The approach to meta-analysis that identifies different categories within the data for calculation and reporting of the related statistics by category allows for the comparison of different categories. Additionally being able to test if there is more variation in the different studies than would be expected from sampling error alone allows for the testing of the assumption that data is comparable (Borenstein et al., 2009; Ellis, 2010; Lipsey & Wilson, 2001). This focus on the variation in effect size rather than trying to develop one grand mean is a more subtle and focused way of understanding the data and its implications (Ellis, 2010).

One long-standing issue in trying to aggregate the information from many researchers and studies is dealing with the differences in methodological quality across the body of knowledge (Cooper et al., 2009). Excluding studies of questionable quality is

one approach and the previously mentioned best evidence synthesis (Slavin, 1995). Clear rules for methodological quality are not black and white, and many of the studies of questionable methodological quality may contain important knowledge (Cooper et al., 2009; Lipsey & Wilson, 2001). In the process of the systematic review, the conditions of what is acceptable methodological quality are documented and coding of the research studies is based on that framework. Studies can then be compared to understand if there is any difference between good and bad studies. Then a decision is made, as part of the process, to include or exclude specific studies (Borenstein et al., 2009; DeCoster, 2004; Lipsey & Wilson, 2001). The qualitative differences between studies become subject to the coding schema of the analysis, and the impact they have on the overall outcome can be identified (DeCoster, 2004; Lipsey & Wilson, 2001).

The results of the systematic review are only as good as the process used (DeCoster, 2004, p. 3). It is possible to do a bad meta-analysis (Ellis, 2010). The visibility of the process, what was included and excluded, why those decisions were made and how the information was coded and processed should always be presented. The overt visibility of the process supports a much easier detection of a poor analysis than with other forms of aggregation (Cooper et al., 2009; Cooper, 2009; Lipsey & Wilson, 2001)

The overstatement of the outcome because of the bias to publish significant findings (DeCoster, 2004; Ellis, 2010; Lipsey & Wilson, 2001) continues to be an issue for the systematic review even though there is a significant and systematic attempt to include relevant unpublished work. Even an exhaustive type of search that is part of the

methodology of the systematic review (Cooper et al., 2009; DeCoster, 2004; Ellis, 2010; Lipsey & Wilson, 2001) is unlikely to achieve one hundred percent accuracy in search results and so the meta-analysis should always be considered to have some publication bias.

Summary

There was evidence from the literature that the experience of surviving breast cancer may be different for African American and European American women. Some of the findings from studies of long-term survivors were inconsistent. Using meta-analysis to understand the size and direction of effects from the primary research into HRQOL was designed allow a deeper understanding of what had been reported.

In Chapter 3 I defined the plan and process of the study. Meta-analysis requires that all steps in the study be fully documented (Lipsey & Wilson, 2001; I. Wilson, 2004). The methodology chapter provides documentation of the process used and the coding schema (S. J. Wilson, 2011). The coding approach for data is defined, the code pages documented (Cooper et al., 2009), and the database organization is described. The effect sizes and related statistics were then computed (D. B. Wilson, 2010a), and the outcome of that process examined, interpreted and reported (DeCoster, 2004; Lipsey & Wilson, 2001; Randolph, 2009; Slavin, 1995).

Chapter 3: Research Method

Introduction

This chapter provides a description of the design of the systematic review and meta- analysis (Cooper & Hedges, 2009) and the rationale for its use in this study. The methodology design was based on the approach endorsed by the Cochrane Collaboration (Higgins & Green, 2011) and the Campbell Collaboration (2009).

The chapter begins with the problem definition, which includes the eligibility requirements for a research study to be included in the review, and the associated implications for the four other major sections of the methodology (The Campbell Collaboration, 2011; Cooper, 2009; Cooper & Hedges, 2009; Higgins & Green, 2011). The process continues with the search for and collection of data, the coding of information from the included studies, the analysis of data (including the meta-analysis), and the interpretation and reporting of findings (Higgins & Green, 2011; The Campbell Collaboration, 2011). The process and methods for collecting, storing, and managing the data were described, and the sample code pages for the database were provided.

The process of the study and methodology of the analysis of the included studies were described, and a description of the approach to documentation is provided based on the PRISMA documentation standards for systematic reviews (Moher et al., 2009).

Research Design and Approach

Process of Meta-analysis

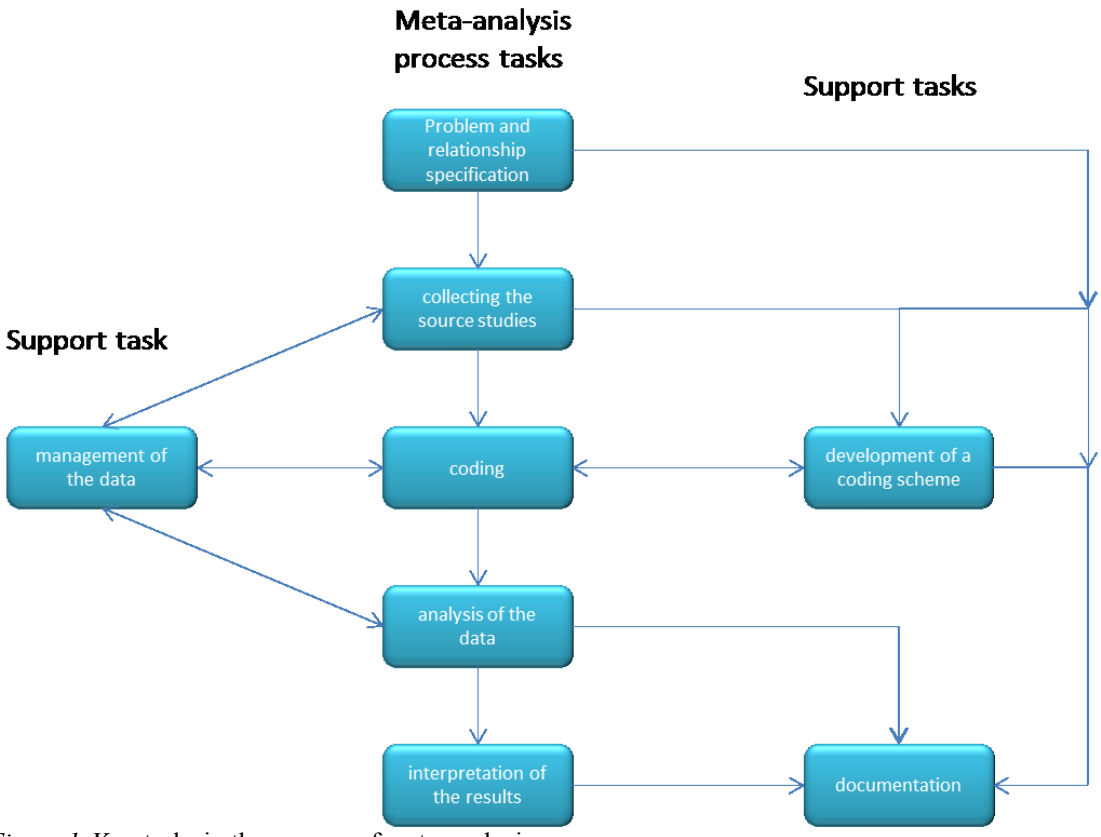

Figure 1. Key tasks in the process of meta-analysis..

Problem Specification and Study Retrieval Approach

The research questions associated with this problem statement are as follows:

1. Compare the effects of survival for more than 5 years post treatment on HRQOL of African American Breast cancer patients diagnosed with Stages 0-II with those of patients of European American racial identification?
2. Is enough data available in the population of studies to observe the impact of age on the effect size?
3. Is there enough data on SES in the population of studies to identify its impact as a moderating variable?
4. Can the choice of HRQOL instruments be identified as having an impact on the effect size seen in the research?
5. Can subgroup analysis identify differences in components of HRQOL?
6. The null hypothesis for the study is that the mean effect size is zero (random effects model; Borenstein, et al., 2010).

The SMD of HRQOL is the effect size being measured in this meta-analysis.

Identification and Definition of the Variables

HRQOL. The dependent variable in this relationship was the psychosocial experience of survival as measured by HRQOL. This composite concept is used in an attempt to encompass the multiple dimensions of survival and to show how survival from chronic disease can be characterized and described (Ashing-Giwa, 2005b; CDC, 2011; Ferrans, Zerwic, Wilbur, & Larson, 2005).

Researchers have used HRQOL to assess the impact of illness on a person (Ashing-Giwa, 2005b). It is a construct composed of physical, functional, psychological, social, spiritual, and sexual well-being (Ferrans et al., 2005). According to the CDC (2011), HRQOL is a valid indicator of resource and service needs and may be a "more powerful predictor of mortality and morbidity than many objective measures of health" (What is health-related quality of life? section, para 3).

Researchers have also perceived different components of this overall measure as more important or relevant than others. They chose their measurement instruments based on the qualities they were choosing to measure (Wilson, 2004).

Scholars consider HRQOL a viable construct (Fryback, 2010) even though there has been debate about the measures and the need for standardization (Fryback, 2010); several studies provided comparisons of those most used in breast cancer research (Ganz & Goodwin, 2004; Montazeri, 2008). Most of the studies retrieved in the pilot search that used HRQOL did not break the data down into the constituent components but rather reported the overall measure. (Note: Chapter 2 has a more detailed discussion of HRQOL in research for breast cancer.)

For this study I planned to use the overall measure of HRQOL and code the different instruments used as part of the overall data collected from the studies. Where data were available in the studies, the different dimensions of the construct were coded, and a separate meta-analysis to identify impact was planned and to some degree executed. During the analysis phase, an assessment was planned of the impact of the

different instruments on overall effects size to see if there was any impact that should be considered in the interpretation of results.

Race. The American Cancer Society (2010, p. 4) used the racial categorization of White, African American, Asian American/Pacific Islander, Hispanic/Latino, and American Indian/Alaskan Native. In this study only the African American and European American (White, per American Cancer Society, 2010) categorizations were of interest. Operationally to be included for consideration a study had to have had at least one of those two racial categories as part of its population.

The categorization of race in the United States has a history of political, cultural, and historical implications that include discrimination at the individual, societal, institutional, and structural level (Betancourt & López, 1993; Krieger, Williams, & Moss, 1997; Stratton, Nepaul, & Hynes, 2007; Thompson et al., 2008). The variable is intimately confounded with SES and the related concept of social class with the implications of access to resources, prestige, and power (Williams, 1999; Williams & Jackson, 2000; Williams, Lavizzo-Mourey, & Warren, 1994).

Race and ethnicity are often confused (Betancourt & López, 1993) or used interchangeably (Stratton et al., 2007). In this study only the designations used by the study authors were considered, and the complexity of the interaction between race and ethnicity (Betancourt & López, 1993; Stratton et al., 2007) was outside the study scope.

In at least one study where SES was distinguished from race in breast cancer experience (Bradley et al., 2002), African American women were shown not to be statistically significantly different than European American women for stage at diagnosis,

treatment and survival. However, this finding was not sustained by research that focused on identifying if SES and race can be separated in looking for causal factors in breast cancer. When looking at stage of diagnosis in breast cancer and how it relates to race and SES Lantz et al. (2006) found race was still a significant differentiation factor. These studies were based on an earlier part of the breast cancer journey than my study, but I planned to examine the relationship between SES and HRQOL however data were not available to support that work.

Age. Age was planned to be coded for the selected studies. Studies retrieved did not have consistent age identification. Sufficient data was not available to do a secondary assessment of the impact of age.

Diagnostic categories. The variable disease stage, which can have a profound effect on survival quality and mortality, was limited in this study to those with local or early regional disease at diagnosis (Stage0, I, or II). Treatment characteristics can also influence survival quality (Casso et al., 2004; Ganz et al., 2002; Giedzinska et al., 2004; Northouse et al., 1999) but were not included in survivor research often enough to analyze as moderator variables.

PICOS and SAMPLE assessment. The Cochrane and Campbell collaborations use a methodology of assessing the viability of the research question in a systematic review. The PICOS (Higgins & Green, 2011) approach was a way to ensure that there were effective operational definitions for the key constructs of the review. The following is the PICOS assessment for this review:

Table 1

PICOS Assessment of Research Question (Higgins & Green, 2011)

Category	Description
Participants/people	Women who have survived breast cancer having been diagnosed with Stage 0-2 of the disease
Intervention	At least5 years elapsed since cessation of primary treatment
Comparison	Differences between African American and other racial categorizations. If data available impact of age on that comparison
Outcome	Measure of HRQOL as measured by an instrument.
Study characteristics	Quantitative studies where enough data were provided or can be retrieved. The racial definitions must be close enough to be substantively the same as those used in this study. Age and SES were not essential data for the inclusion of a study.

Table 2

SAMPLE Assessment of Research Problem

Question	Answer
Is it Specific?	The PICOS process shows that operational definitions for the primary variables were developed, and inclusion and exclusion criteria can be stated Ad Hoc.
Is it Answerable?	The question was answerable given that the research studies can be retrieved and the data published. See section on literature retrieval for a discussion on bias in publication.
Are there measurable constructs?	The construct of HRQOL is measureable. The unknown question was how much data was available on the variables age and SES. Race is a categorical variable that is not always measured in the same categories. One of the inclusion criteria for studies was that the definition of race should be close enough to that of the American Cancer Society(American Cancer Society, 2010)
Is it Practical? i.e. relevant for policy/practice.	If we could know the differences between women then changes in treatment and support could be identified. An overview of research provided a more viable view than a single study.
Is it logical?	Health outcomes in other areas can be seen to vary by racial categorization (Williams, 1999). It was logical to investigate if breast cancer survival was different across racial categories.
Is it empirical? Can we obtain answers using observable evidence?	If the data were available to be observed then the questions were answerable.

Note: Adapted from The Campbell Collaboration (Producer) (2011) *Problem formulation, Jeffrey C. Valentine* [Video]. Material presented in video.

The SAMPLE assessment (The Campbell Collaboration, 2011), tests the viability of the research question in the light of the effort and focus (Cooper, 2009) required to complete the review.

Setting and Sample

Systematic reviews, whether they include meta-analysis or not, have a similar action path to most other empirical research that deals with people, the primary difference is that the sample is a population of studies that are surveyed not a population of people (Cooper & Hedges, 2009; The Campbell Collaboration, 2011). This section of the chapter deals with the identification, and retrieval of the population of studies to be used in the review.

Collecting the Source Studies

In part the value of meta-analysis lies in the inclusion of all relevant research (Ellis, 2010; Lipsey & Wilson, 2001). Ideally this is all research where the effect of interest is the focus of research, and there is a statistically equivalent form of the findings (Ellis, 2010). Ideally, all languages, and both published and unpublished research would be included (Ellis, 2010; Lipsey & Wilson, 2001).

The search process attempted to include all relevant research (Ellis, 2010; Lipsey & Wilson, 2001). Several factors can be identified as having an impact on the completeness of the research. Only research that had been published in some form that was accessible through search engines was able to be included in the search, and because the research was focused on African American and European American women, it

primarily was focused on research in English and published in North America (Ellis, 2010; Lipsey & Wilson, 2001).

The ability to retrieve and examine all research in the possible population of studies is often limited by both time and availability of the studies (Lipsey & Wilson, 2001). This limitation, and the tendency for published studies to have a statistically significant result, known as publication bias (Ellis, 2010), can severely limit the population that is included in the meta-analysis. The process for sourcing the data included an attempt to identify research that was not published, however it must be accepted that the population of studies included was not exhaustive. Time to complete the search was a limiting factor although an assessment of how many additional studies might have been included cannot be made (Lipsey & Wilson, 2001). All studies that were identified as potentially relevant were able to be accessed in full text (Lipsey & Wilson, 2001).

There is debate in the meta-analysis literature (DeCoster, 2004; Ellis, 2010; Lipsey & Wilson, 2001) relative to defining the quality of the research that is included. While it is possible that badly designed research may provide bad data (Ellis, 2010) until the coding is underway, and the quality of the studies could be assessed, no studies could be excluded from retrieval on the grounds of methodological inadequacy. At the time of sourcing of the studies, those that were methodologically or statistically suspect were identified for examination and decision about inclusion. However, because of the scarcity of data that were available, rejection of studies on methodological grounds wasn't relevant.

Study Eligibility Criteria

The framework for identifying key criteria for inclusion of studies in the meta-analysis was adapted from the approach used by the Cochrane and Campbell Collaborations (Hammerstrøm, Wade, & Jørgensen, 2010; Lefebvre, Manheimer, & Glanville, 2011) and from Lipsey & Wilson, 2001(pp. 16–23).

Distinguishing features. The outcome or dependent variable was a measure of HRQOL. The identified HRQOL measures commonly used in Breast Cancer survival research are listed in Table 3. No additional instruments were identified during study retrieval, so the code page was not updated. These were primarily sourced from five key systematic reviews of HRQOL in breast cancer (Ganz & Goodwin, 2004; Goodwin, Black, Bordeleau, & Ganz, 2003; Mols et al., 2005; Montazeri, 2008; Perry et al., 2007). Table 3 lists the instruments used in the group of studies included in the analysis.

Research respondents. Research respondents were on the primarily female although some studies had a small number of male breast cancer patients. Where research included male breast cancer patients and their data was not reported separately the study could not be included in the analysis.

All respondents had a diagnosis and were treated for early-stage breast cancer. All research was for populations that had an average survival time greater than 5 years post diagnosis. It should be noted that some researchers included survivors who were less than 5 years and did not report the results separately. These studies (n=5) where the mean survival was greater than 5 years have been included in the study population.

Table 3

HRQOL Instruments Used in the Studies Included in Analysis

Instrument abbreviation	Instrument name	Category	Date	Number of studies
CARES- SF	Cancer Rehabilitation Evaluations System-Short Form	Cancer	1991	2
EORTC QLQ-C30	European Organization for Research and Treatment of Cancer Quality of Life Questionnaire - 30 Item	Cancer	1993	4
FACT - B	Functional Assessment of Cancer Therapy-Breast	Breast	1997	5
LoL	Ladder of life	General	1965	1
POMS(PMS)	Profile of mood states	Psychological	1981	2
QLIC(F&P)	Ferrans and powers Quality of life index-Cancer	General	1990	9
QOL-CS	Quality of Life Cancer Survivors	General	1996	4
SF-36	Medical Outcomes Study Short Form 36 (MOS-SF36)	General	1993	31

Research methods. This study was designed to include a meta-analysis as part of the systematic review so only quantitative studies were included, effects had to be reported in a statistic that could be transformed into SMD and the subject population had to be clearly identified (Ellis, 2010; Lipsey & Wilson, 2001). Study methodology was not restricted to Randomized Control Trials (RCT) or Clinical trials (CT) as Quality of

life studies outside of the timeframe of primary treatment can often only be conducted on a convenience sample (Ganz & Goodwin, 2004)

Timeframe. Research was included where it was relevant to the topic and included studies from 1998 through 2012.

Publication type. Searches of materials were constructed to "include published journal articles, books, dissertations, technical reports, unpublished manuscripts, conference presentations" (Lipsey & Wilson, 2001, p. 19) and potentially online publications, as well as more traditional methods. Availability of all types of material was variable so type of publication was identified. Sources of research and efforts to retrieve studies were documented.

Journal articles and dissertations were the final publication types included in the study. Other types of publications were retrieved but none met criteria for inclusion (Lipsey & Wilson, 2001, p. 19). Some publications were only online publications. During planning of the research it was expected that unpublished research would be difficult to locate (DeCoster, 2004; Lipsey & Wilson, 2001), this proved to be the case and no additional unpublished research was identified.

Methodological quality. Lipsey and Wilson (2001) point out that the methodological criteria that are important in any given meta-analysis are likely to be specific to that analysis. In a review of HRQOL in Breast Cancer that focused on how HRQOL could support decision making in breast cancer treatment Goodwin et al. (2003) used only Randomized Clinical Trials (RCT). This focus was relevant because of the nature of decision making during treatment, and the ability to use the findings as an

outcome measure in already existing research into the impact of different treatment options. In studying the population that was more than 5 years post treatment, and especially with a focus on racial or SES characteristics, this study was not looking at the outcome of an intervention but rather at the combination of uncontrollable factors in lives. Consequently, it was methodologically irrelevant that the studies be RCT but still important that they be quantitative in nature to allow for statistical analysis of results over multiple studies.

Observer bias can be seen as a significant issue in judging methodological quality (Lipsey & Wilson, 2001). In an attempt to reduce this, the decisions about the rules for methodological inclusion were made in advance of surveying the data.

The following methodological criteria were the minimum requirements:

- Study must be quantitative in nature
- Statistical findings must include sufficient information to transform to the effect size SMD.
- Data of statistical outcomes must be available for at least a racial categorization of African American and European American or synonyms of those categorizations.
- Racial classification must be that used by the American Cancer Society (2010, p. 4) or understandable in that context.
- Study must use one or more HRQOL instruments that were identified in this section or whose validity and reliability can be independently validated.

- Population must be clearly identified, and preferably participant numbers identified.
- Study must be in English.
- Peer review was not a necessary criterion as it is possible that the "gray" literature including dissertations or government reports may have relevant study information. If a report was not peer reviewed, it must be published under some authoritative body supervision.
- Where studies that met all other criteria for inclusion but had insufficient data resulted in a largely unsuccessful attempt to retrieve the needed data from the author before rejecting the study.

The more restrictive the methodological criteria, the more likely, that data would not be included in the analysis (Lipsey & Wilson, 2001). The methodological characteristics of the research studies were collected during coding with the plan of enabling a moderator analysis of different methodological characteristics to be performed so that their impact on the mean effect size could be identified. This was not possible with the limited number of reports that could be included in the study.

One way of assessing if studies were "good" or "bad" research (Ellis, 2010; Lipsey & Wilson, 2001) is to assess the statistical power of the studies being combined so that we know if each study has the power to "detect an effect size equivalent to the weighted mean" (Ellis, 2010, p. 127) of all studies. In this analysis, all studies that met the inclusion criteria were included in the analysis. An assessment of the difference in

the mean of the effect sizes based on the exclusion of insufficiently powered studies was planned, but not relevant in the size of the population.

Retrieval Strategy

Retrieval of documents for possible inclusion into the database began with the exhaustive documentation of the approach and continued through all actions taken to find, sort, and include or reject studies (DeCoster, 2004; Ellis, 2010; Lipsey & Wilson, 2001). It was expected that studies relevant to this review would be in different databases and categorized in different ways (Hammerstrøm et al., 2010). In order to reduce bias in the search and retrieval of studies a strategy of high sensitivity was pursued even though relatively low precision (many irrelevant studies) in the initial recovery (Hammerstrøm et al., 2010) was the result.

There are five major groups of strategies that can be used in systematic literature retrieval (Hammerstrøm et al., 2010; Higgins & Green, 2011; White, McAuley, Estabrooks, & Courneya, 2009). These were searches in subject indexes and computer bibliographic databases, searching citation indexes, "snowballing" (also called pearl growing, or footnote chasing), browsing or hand searching, and consultation.

Bibliographic databases and subject indices and citation indices. Initial searches using the Walden Library Database of journals and internet search engines (e.g. Google) were used to retrieve published bibliographies in the area and review articles (DeCoster, 2004). The results from this initial search were used to build both the keyword search list and to find an initial list of the key authors in the field (DeCoster, 2004; Lipsey & Wilson, 2001), as well as candidate studies. An initial keyword search

list was built from published bibliographies and review articles (DeCoster, 2004). Table 4 lists the keywords and search arguments.

In all 18 databases or families of Databases were searched for reports of studies that met the criteria, a list of these available in Table 5. Web searching is considered a good secondary search strategy (Hammerstrøm et al., 2010). It was used as part of the retrieval process for those reports that were retrieved in full text and to broaden the search. The search engines in the database proved remarkably efficient in identifying reports that could be considered. While conference proceedings were identified using internet search engines, no new usable reports were added to the database (DeCoster, 2004).

Additionally a strategy of searches was followed using the PICO assessment developed in section related to the research question. The PICO was used as a framework to generate synonyms for keyword searching as in Table 4. A keyword search was performed against the target databases (see Table 5) (Hammerstrøm et al., 2010; Lefebvre et al., 2011), with results entered into the bibliographic spreadsheet (Lipsey &Wilson, 2001). In addition to keywords generated from synonyms, each database had a specific set of search terms and indexing strategies that were added to the keyword search sequences. Web searching is considered a good secondary search strategy (Hammerstrøm et al., 2010) which provides a possibility of published an unpublished studies not otherwise found. This strategy allows for the generation of data about conferences where still unpublished but potentially usable studies were likely to

have been presented (DeCoster, 2004). Web searching was used in addition to the searching of databases and results were added to the bibliographic data base.

Table 4

Search Arguments Used

argument	rel	argument	rel	argument	rel	argument
				African		
breast cancer	and	HRQOL	and	American	and	survivor
breast cancer	and	HRQOL	and	early-stage	and	survivor
breast cancer	and	HRQOL	and	survival	n	full text
breast cancer	and	HRQOL	and	survivor	n	full text
breast cancer	and	HRQOL	and	black	n	full text
breast cancer	and	HRQOL	and	minority	n	full text
breast cancer	and	QOL	and	survivor	n	full text
breast cancer	and	QOL	and	survivor	and	long term
Breast carcinoma	and	HRQOL	and	survivor	n	full text
Breast carcinoma	and	QOL	and	survivor	n	full text
women	and	breast cancer	and	>5 years	and	HRQOL
breast cancer		HRQOL			n	full text
breast cancer	and	QOL	and	Survival	n	full text
				African		
breast cancer	and	HRQOL	and	American	and	survival
breast cancer	and	QOL	and	black		

Table 5

Databases Used in Search

Database Name	Source
Academic Search Complete	Walden Library
Cochrane central register of controlled trials	Walden Library
Cochrane collection plus	Walden Library
Cochrane database of systematic reviews	Walden Library
Database of abstracts of reviews of effects (DARE)	Walden Library
Dissertations and theses	Walden Library
Dissertations and theses at Walden University	Walden Library
ERIC	Walden Library
Expanded Academic ASAP	Walden Library
Fdsys	Walden Library
MEDLINE with full text	Walden Library
OVID Nursing Journals	Walden Library
PROQUEST Central	Walden Library
PROQUEST Health and medical Complete	Walden Library
PROQUEST Nursing and allied Health source	Walden Library
PSYCARTICLES	Walden Library
PSYCINFO	Walden Library
PubMed	Walden Library
SAGE Premier	Walden Library
Science Direct	Walden Library
Science Journals	Walden Library
Soc INDEX with Full Text	Walden Library
The Evidence Network	http://www.kcl.ac.uk/schools/sspp/interdisciplinary/evidence
The Health Inter Network Access to Research Initiative (HINARI)	www.who.int/hinari/en/

Database Name	Source
CITATIONS	
Web of Science Citations	Walden Library
Grey Literature	
SIGLE	opensigle.inist.fr/
National technical information service NTIS	Walden Library
PSYCHEXTRA	Walden Library
Social Care Online	www.scie-socialcareonline.org.uk/search.asp

Snowballing. Also called branching, is an approach which improves the likelihood of finding other potentially relevant studies by searching the reference lists from retrieved studies (Hammerstrøm et al., 2010). In addition to allowing for the retrieval of other studies, new keywords for searches were added by examining the indexes used for useful retrieved studies and examining the reference lists of studies and reviews (Hammerstrøm et al., 2010; Lefebvre et al., 2011).

Browsing or hand searching. While it was possible that studies would be found by searching in hardcopies of journals, the process is time consuming, and most benefit can be achieved by scanning the Table of Contents for journals where other studies have been found (Hammerstrøm et al., 2010). Hand searching was very limited as search criteria had begun to return duplicates consistently before hand searching was begun.

Consultation. Authors who have published more than one article in the field may have other studies that were unpublished (DeCoster, 2004). After research approval, email requests were sent to authors asking if they have unpublished studies that they would allow to be included in the meta-analysis. No responses were received.

As expected there were many studies that would have met all criteria and allowed for the execution of a meta-analysis if the data on African American BCS had been presented separately to that of European American BCS. To attempt to overcome this issue, I sent emails to all primary researchers where an email address could be identified. In total 47 emails were sent. Two researchers answered the email but neither was able to provide data.

Processing and managing the studies. Once studies were identified, the list was examined and any duplication was removed. A manual accept or reject decision was made based on the criteria identified above (Lipsey & Wilson, 2001). The reason for sorting a study into the "reject", "accept" or "needs further work" based on the title and abstract was noted in the database. If there was a need to read the full article to make the decision, initial coding of the study was done at the same time, to reduce the amount of rework. Only one study was identified that met all criteria.

It was possible that a study that should have been included was rejected. This rejection was one of the areas where the subjectivity of the researcher may have impacted the results (Lipsey & Wilson, 2001). To ensure that this can be evaluated by another researcher in the future, the reasons for exclusion of any retrieved studies were included in the documentation.

As this is a subjective process (Lipsey & Wilson, 2001), all data were listed in the retrieved database. Rejection reasons were identified. These data are available separately on request and contain the database used to manage research studies Lipsey & Wilson

(2001). Microsoft Excel 2010 was used to manage the acquisition of the study data. The data layouts and code pages are available in the Appendix

A journal of actions and decisions was maintained in an Excel spreadsheet during the process. This journal includes the search parameters, a summary of results, and the actions taken that were then documented in the bibliographic spreadsheet and the Zotero Database (D. Cohen & Takats, 2010).

Lipsey & Wilson (2001) recommend the setting up of a database to manage the research studies. Microsoft Excel was used as the data collection database because of its flexibility and ease of dissemination. A database to keep a "meticulous accounting" (Lipsey & Wilson, 2001, p. 23) of the search and collection of research studies for analysis was kept. Keeping this accounting required that all potentially eligible studies that were retrieved were entered into the database. The documentation of this process in Excel spreadsheets is available on request, but is not included with the dissertation.

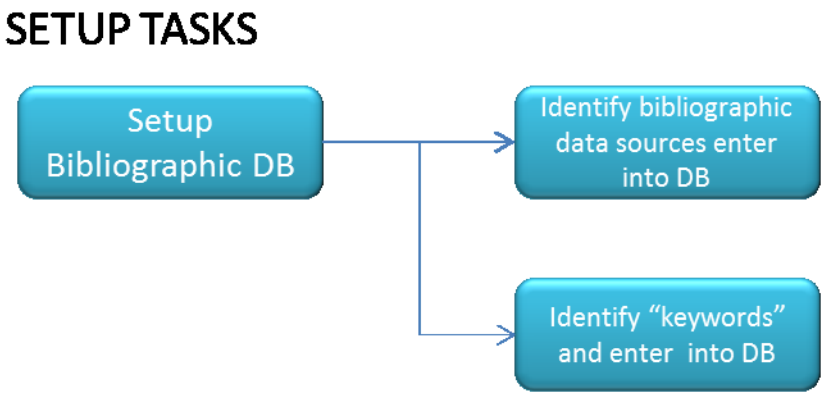

Figure 2. Process diagram setup steps for the search.

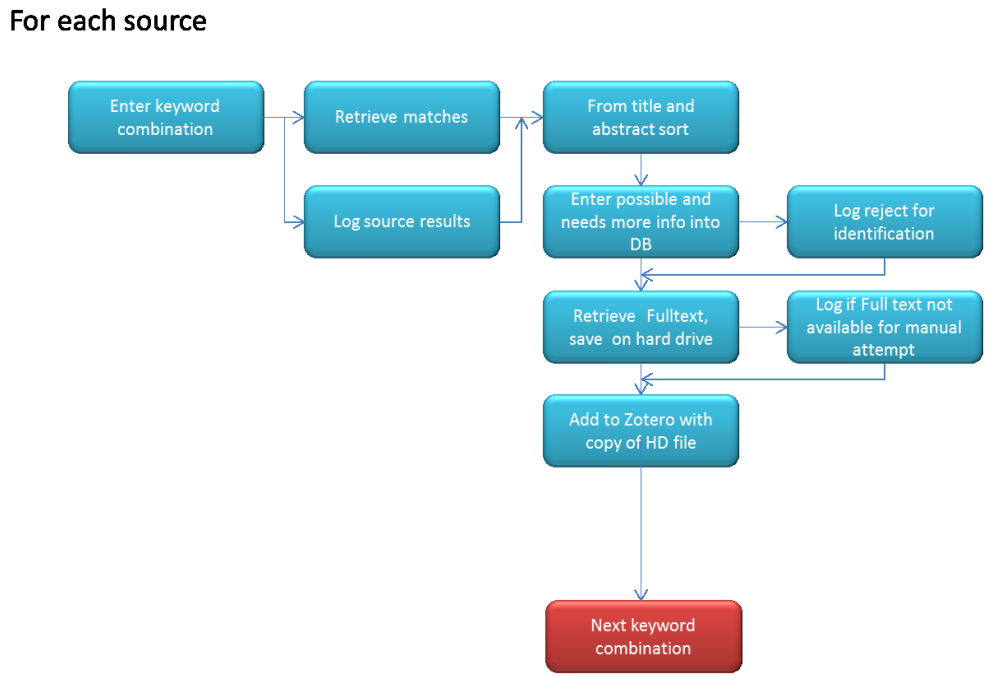

Figure 3. Process diagram including the steps for search and recording.

Table 6 below contains the definition of the columns used in the excel Database to record the initial retrieval of studies. Columns marked with an asterisk were required for all entries.

Once the study was retrieved and entered into the excel database it is also added to the Zotero DB for the content articles. A separate Zotero DB is maintained for all other material used in this dissertation. All studies saved to the hard drive and a copy added to the Zotero DB that is maintained on the internet. An additional back up is maintained on network drive.

Table 6

Initial Data Coded at Retrieval of Study

Column heading in DB	*Coding Required (*)*	*Definition*
		Unique number assigned to every study included in the analysis. This is the database identifier, the file identifier and is physically on the paper copy.
Study ID	*	*Sequential number assignment starts at 1000*
Title	*	*Study title*
Initial Author	*	*First Author*
Date Published	*	*Publication date*
document status	*	*1= returned in search, 2= relevant to study , 3= background information, 4= possible study for inclusion, 5= study for coding, 6= coded, 7= invalid or withdrawn, 8 = examined, not included*
In bib software	*	*Yes/ No*
Full text	*	*Yes/ No*
Full text retrieval date		*Date of retrieval of full data*
Journal	*	*Source Journal name*
Volume	*	*Volume of journal*
Issue	*	*Issue of journal*
Page Begin	*	*Page start of article*
Additional Authors	*	*Additional authors*
Abstract	*	*Usually the author summary of the content of the study*
Search sequence	*	*Reference search control. Sequence number is made of combination of search arguments and search retrieval source.*
Search date	*	*Date the initial search was complete*
SourceDataBase	*	*category of codes for source database, see data code page*
Notes		*Free hand information that should be carried about the study*
Reason for not including		*Description of the reason for not including the study. Where a study did not meet the criteria, enter that in criteria field*

Column heading in DB	*Coding Required (*)*	*Definition*
Code for exclusion		*1= not relevant population, 2= full text could not be retrieved, 3 = did not meet exclusion criteria, 4= Multiple reports of the same study,*
Criteria not met		*1 = Study must be quantitative in nature 2 = Statistical findings must include sufficient information to transform the effect size SMD. Reference table of possible statistics in Section Coding, Effect size calculations. 3=Data of statistical outcomes must be available for at least a racial categorization of African American and European American or synonyms of those categorizations.4= Racial classification must be that used by the American Cancer Society (2010, p. 4) or understandable in that context, 5= Study must use one or more HRQOL instruments that were identified in this section or whose validity and reliability can be independently validated.6= Population must be clearly identified and preferably participant numbers identified.7= Study must be in English.*

Note. At least items marked with asterisk must be coded even for articles rejected on initial pass. Full bibliographic code page is in Appendix B.

Process Pilot Data. For the purposes of illustration and testing of the process a small sample of potential studies was retrieved. A MEDLINE with full text search using the search parameters "breast cancer" and "survivor" and "HRQOL" retrieved three studies, all of which passed initial scrutiny. Additional records from previous test searches were chosen at random to process. This step was a taken to test if there appeared to be enough data available to conduct the study. The only study where and SMD could be calculated overall was retrieved during the pilot. The pilot suggested that there would be sufficient data available**.**

Documentation of the Results. In addition to maintaining an ongoing log and bibliographic database file. The search was documented using the Preferred Reporting Items for Systematic reviews and Meta-Analysis (PRISMA) guidelines (Moher et al., 2009).

Reasons for rejection of reports from the processing steps during retrieval are in Tables 7 and 8 below.

Table 7

Reasons for Rejection of Reports on Review of Title and Abstract

Rejection categories in title and abstract review	# of studies
Not related to breast cancer but had quality of life component	10
Met most criteria but data not presented	29
Related to instruments but without data that could be used	107
Not English	27
Meta-analysis or systematic review	67
Breast cancer related but not quality of life outcome	106
Related to prevention of breast cancer	75
Population not in scope, e.g. Latina	7
Research conducted in Qualitative paradigm	139
Editorial or not study report	15
Data related to an early-stage of the trajectory or stage was not identifiable	356
Related to treatment of breast cancer or its sequelae without usable quality of life data	1159
Identified as non US and not in other categories	10
Useful background information but not usable for study	219
Other cancers, other conditions	1641
Total	3967

Table 8

Reasons for Rejection of Reports on Review of Full Text

Rejected from study on full text examination	# of studies
not Breast cancer	3
Not > 5 years mean	129
duplicates of reports	11
instrument testing not usable	4
could not be retrieved	8
not quantitative	5
wrong population	5
Measure not quality of life	66
not a study report	74
wrong stage of cancer	7
treatment related	1
not US population	15
Total	328

Coding Process

The purpose of coding the studies retrieved in meta-analysis is to obtain information using a process that is designed to minimize bias (Cooper, 2009). Information was retrieved from the published reports, processes to handle missing data (Pigott, 2009) were executed, and if a study had multiple reports, or multiple effect sizes reported which study or effect size to include was identified (Cooper, 2009; Lipsey &

Wilson, 2001; D. B. Wilson, 2011a). Processes and documents that identified what to code (Cooper, 2009; Lipsey & Wilson, 2001), how to code (Cooper & Hedges, 2009; Lipsey & Wilson, 2001; S. J. Wilson, 2011), and how to manage the data (Lipsey & Wilson, 2001) were prepared so that anyone involved in the coding could be trained (Cooper, 2009) to execute the process in as similar way as possible (Cooper, 2009). This documentation also allowed another researcher to duplicate the process if desired (Cooper, 2009).

Studies were eliminated during the process of coding. The process was designed so that minimal work was lost if a study did not meet the criteria. After the decision to eliminate a study was made, no more data were recorded about that study. All reports had initial bibliographic data retrieved, but it was not until the report of a study was accepted into the review that the major coding was executed.

Studies that entered coding had the article full text retrieved and stored locally, and the bibliographic data were entered or updated (S. J. Wilson, 2011). Study date and population were checked against the database to ensure that this was not a multiple report of the same study (this was dealt with as a separate process for all studies that had multiple reports) (S. J. Wilson, 2011). If it was a single report of a study, data from the study were coded as per the coding template (Cooper, 2009; Lipsey & Wilson, 2001; S. J. Wilson, 2011), and the effect size statistic or statistics were calculated (Borenstein et al., 2009; Lipsey & Wilson, 2001; D. B. Wilson, 2011a; S. J. Wilson, 2011). If the study had relevant population and outcome measures, but the required data were not provided, the study was moved to a separate process that required manual attempts to retrieve the

needed data, for example contacting the authors (Hammerstrøm et al., 2010). All studies for which data could not be retrieved for inclusion were recorded and excluded from the analysis (Hammerstrøm et al., 2010; S. J. Wilson, 2011).

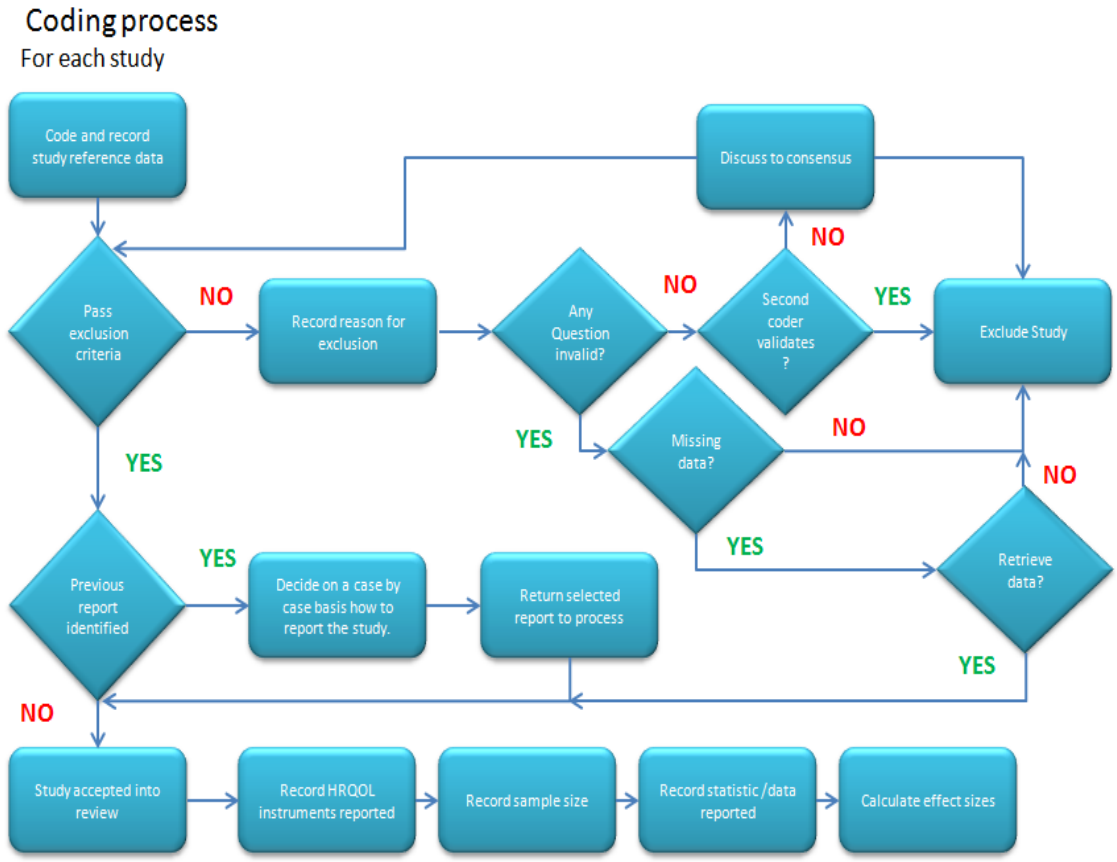

Figure 4. Steps to complete the coding process.

Code and Record Study Reference Data

Once a full text version of the study was retrieved the bibliographic entry was updated if needed and the study passed into coding. At this point the data recorded about a study were the same as recorded in Table 6, with the exception that the code for full text article retrieved was updated to "yes" and the retrieval date entered. Attempts

continued during the coding process to retrieve all articles where the title or abstract suggested the study was relevant. When all attempts at retrieval failed the study was discarded, and the reason recorded to ensure transparency of actions (Lipsey & Wilson, 2001; S. J. Wilson, 2011).

Pass Exclusion Criteria. The exclusion criteria set out in Table 9 were the operational definition of the studies that form the population analyzed in this review.

Table 9

Exclusion Criteria for the Study

	Criteria
1	Study must be quantitative in nature
	Statistical findings must include sufficient information to transform the effect size SMD.
2	Reference table of possible statistics in Section Coding, Effect size calculations.
	Data of statistical outcomes must be available for at least a racial categorization of African
3	American and European American or synonyms of those categorizations.
	Racial classification must be that used by the American Cancer Society (2010, p. 4) or
4	understandable in that context.
	Study must use one or more HRQOL instruments that were identified in Table 4 or whose
5	validity and reliability can be independently validated.
6	Population must be clearly identified and preferably participant numbers identified.
7	Study must be in English.

The formulas for the calculation of the SMD are listed in Table 11. If a report of a study did not have sufficient information to calculate the effect size, an attempt was made to contact the author and obtain the relevant information. When that failed, the

study was excluded from the review. If a study failed to meet any other criteria, it was removed from the study, and the reason noted.

It was planned that any doubt about a study's inclusion or exclusion would require a second coder to assess it without being aware of the original decision. If their assessment was different from the first, then a discussion was planned to take place until both coders were in agreement. No studies required this process.

Multiple Reports of a Single Study. It is possible that multiple reports were published reporting a single study (Cooper, 2009; Lipsey & Wilson, 2001; D. B. Wilson, 2011b). A process to handle studies with multiple reports (DeCoster, 2004; Ellis, 2010) was required. From the multiple reports, a single representative report should be chosen (Cooper, 2009; Ellis, 2010; Lipsey & Wilson, 2001; D. B. Wilson, 2011b). Studies that had multiple published reports, or where multiple effect sizes were reported required a decision on which effect size would be used. In this study, separate analysis were conducted for different instruments, and only one study required the inclusion of two reports as data required was spread over both (Ashing-Giwa, Ganz, & Petersen, 1999; Ashing-Giwa, 1999a).

Where there were multiple effects that were drawn from the same data a decision was made in each circumstance of the most appropriate way to handle the study, either to record all effects separately or to calculate the average effect size (Ellis, 2010).

The following were the decision guidance rules for multiple reports of the same study:

1. The report where the reported population most closely matches this review was the first choice.
2. The report where the statistics allowed the best calculation of effect size
3. Where the reports were consistent or where taken together the reports form a whole view of the study then the effects were averaged.
4. If decision was not clear cut. The plan was to include the earliest published study.

Table 10

Reports Rejected During Coding

Study title	First Author	Pub. date
Data includes non-Breast Cancer population		
Disparities in HRQOL of cancer survivors and non-cancer managed care enrollees	Clauser	2008
Non-standard measures of quality of life used or insufficient studies in group for analysis		
Health-related quality of life in breast cancer survivors of different sexual orientations.	Boehmer	2012
Personality, coping, and quality of life in early stage breast cancer survivors	Caloudas	2006
Benefits from an uncertainty management intervention for African–American and Caucasian older long-term breast cancer survivors.	Mishel	2005
Individual differences in well-being after breast cancer survivorship in older women	Perkins	2007
Predicting Negative Mood State and Personal Growth in African American and White Long-Term Breast Cancer Survivors.	Porter	2006
Cognitive Dysfunction and Its Relationship to Quality of Life in Breast Cancer Survivors.	Von Ah	2009
Fear of breast cancer recurrence	Ziner	2008
Includes recurrent Breast cancer, or > 20 % > stage 3 or unknown		
Long-term adjustment of survivors of early-stage breast carcinoma, 20 years after adjuvant chemotherapy	Kornblith	2003
Depressive Symptoms and Health-Related Quality of Life in Breast Cancer Survivors.	Reyes-Gibby	2012

Study title	First Author	Pub. date
Majority non US participants		
Invariance Testing of the SF-36 Health Survey in Women Breast Cancer Survivors: Do Personal and Cancer-related Variables Influence the Meaning of Quality of Life Items?	Mosewich	2013
Efficacy, toxicity, and quality of life in older women with early-stage breast cancer treated with letrozole or placebo after 5 years of tamoxifen: NCIC CTG intergroup trial MA.17.	Muss	2008
All's Well That Ends Well? Quality of Life and Physical Symptom Clusters in Long-Term Cancer Survivors Across Cancer Types.	Zucca	2012
Population mean < 5 years, undefined or > 20% < 5 years.		
Frequent Search for Sense by Long-Term Breast Cancer Survivors Associated with Reduced HRQOL.	Andersen	2008
A cross-cultural validation of patient-reported outcomes measures: a study of breast cancers survivors.	Ashing-Giwa	2012
Association between current lifestyle behaviors and health-related quality of life in breast, colorectal and prostate cancer survivors.	Blanchard	2004
Quality of life and lymphedema following breast cancer.	Heiney	2007
Breast cancer survivorship: Contributing factors for special populations	Jabson	2010
Functional status of long-term breast cancer survivors: demonstrating chronicity	Polinsky	1994
The Quality of life of African American women with breast cancer	Northouse	1999
Worry of recurrence in breast cancer survivors	Rothrock	2003
Breast cancer in African American women: Validation of a quality of life instrument.	Rowley	2001
Quality of life among older survivors of breast cancer.	Sammarco	2003
Quality of life of breast cancer survivors: a comparative study of age cohorts	Sammarco	2009

Study title	First Author	Pub. date
Exercise in breast cancer survivors: Predicting quality of life with the cognitive-appraisal model of stress and coping.	Wagner	2006
Relationship between quality of life and mood in long-term survivors of breast cancer treated with mastectomy	Weitzner	1997
Data provided was incomplete, adjusted using unknown formulae, or non-standard.		
Lymphedema and quality of life in breast cancer survivors: the Iowa Women's Health Study.	Ahmed	2008
Then and now: quality of life of young breast cancer survivors.	Bloom	2004
Fatigue in long-term breast carcinoma survivors - A longitudinal investigation	Bower	2006
Quality of life for women diagnosed with breast carcinoma in situ	Claus	2006
Quality of Life in Long-Term, Disease-Free Survivors of Breast Cancer: a Follow-up Study.	Ganz	2002
The roles of herbal remedies in survival and quality of life among long-term breast cancer survivors - results of a prospective study.	Ma	2011
Clinical outcomes of ethnic minority women in MA.17: a trial of letrozole after 5 years of tamoxifen in postmenopausal women with early stage breast cancer	Moy	2006
Breast cancer survivors' health-related quality of life: racial differences and comparisons with non cancer controls.	Paskett	2008
Five years later: a cross-sectional comparison of breast cancer survivors with healthy women	Tomich	2002
An Exploratory Analysis of Fear of Recurrence among African-American Breast Cancer Survivors.	Taylor	2012
Health-related quality of life of African American breast cancer survivors compared with healthy African American women.	Von Ah	2012

Coding the Study

Once a report of a study was accepted for the review it was coded. It was planned that if multiple coders were used that they would use the same code pages. No additional coders were required as the number of studies that could be used was so small. As expected, the design of the process required some modification as coding proceeded (Cooper, 2009; DeCoster, 2004; Ellis, 2010; S. J. Wilson, 2011). Accurate documentation of changes was kept so that the path of the study can be followed by another researcher if needed (DeCoster, 2004).

The records for each were linked by the Study ID. Multiple sets of data were collected about the study and stored separately linked to the main bibliographic record by the study ID.

The process was tested by a small number of studies in development, and a pilot 10% of the study population chosen randomly was used initially to test the coding definitions for clarity and relevance. In fact iterative coding of the studies proved a more effective way of developing modifications to the code pages as the numbers were so small (DeCoster, 2004).

With such a small sample size, no sampling for secondary coding was possible to assess the validity of the coding definitions and process (DeCoster, 2004; Ellis, 2010; Lipsey & Wilson, 2001). It was planned that at least 10% of the selected studies would be coded by another researcher. As the number of studies available was so limited no additional researchers were involved in this step. No additional training was required.

Information about the Studies. Once the study was accepted into the review for coding, Information about the report characteristics, the study setting, the participants and the outcomes was collected. Code pages for the collection of data are in Appendix B.

Report characteristics. This section identifies the kind of publication, any associated organization and funding source related to the study (Cooper, 2009). These data were collected to assist in identifying studies where there was multiple reporting.

Study methodology data. Data on the instruments used and the settings in which they were completed, as well as an assessment of the independence of the groups identified in the study were recorded. The actual study date was also collected, where it was available, as this may be different from the publication date and may also assist in identifying multiple reports of the same study (Cooper, 2009).

Participant data. The data collected on participants (Cooper, 2009) were planned to identify the classifications of interest in the review, including race, SES and age. It was hoped that data would be available focused on differences between African American and European American groups, but capturing other data would have allowed for a planned moderator analysis.

Participant outcome data as captured by the HRQOL instruments used were captured in the statistics reported from the study. These data became the effects that were reported and were the basis of the meta-analysis. As only one effect can be incorporated into a meta-analysis (D. B. Wilson, 2011a), where the data cannot be reported in a single effect size, multiple meta-analyses were executed.

Reported statistics and calculated effect sizes. This data sheet was planned to allow the recording of multiple groups, with the associated statistics. It included the calculation of the effect size for the two groups of interest to the review (Lipsey & Wilson, 2001), using the racial categorization of African America/Black and European/Caucasian American/White.

Study methodology. Cooper (2009) identifies two categories of methodological question that require consideration when considering if a study should be included in a review; were the concepts measured in the study consistent and relevant in the review, and if the implementation used supports the level of inference that was planned. The first of these questions was operationally answered by including only studies that used HRQOL measures that were identified prior to data collection. It was planned that if a study was identified that otherwise met the inclusion criteria that used an instrument that was not on that list, a case by case assessment would be made. As no overall meta-analysis was possible, a study that used a one of a kind instrument could not be included. All analysis was done where there were at least two studies that used an instrument.

As this study was about the correlation between naturally occurring categories of subjects and outcomes based on a naturally occurring event, methodologies that would not be acceptable in trying to make a causal inference were perfectly acceptable in this review (Cooper, 2009). The review did not attempt to make any causal inferences about a particular event or intervention, so methodological questions that were related to interventions (Cooper, 2009), or particular events other than the occurrence of early-stage breast cancer were not relevant.

Methodological questions that were related to the ability generalize from the findings (Cooper, 2009) were dealt with in the exclusion criteria. By limiting studies to those that included at least women of either African American or European American racial identification, and who were survivors of early-stage breast cancer, clearly identifies the population to whom the inferences can be generalized. Likewise, the adequacy of the reporting of the statistical tests (Cooper, 2009) was identified in the exclusion criteria as a necessary condition for the inclusion of the study.

It was planned to capture study characteristics in coding (Lipsey & Wilson, 2001) that had possible impact on the outcome, for example if the instrument was completed under supervision or not, or the time interval since the end of treatment. The very small sample did not allow for more detailed analysis that was planned.

Calculating the Effect Size

The plan was to use the SMD as the effect size. This effect size compares two independent groups on the mean of a continuous measure (HRQOL in this review) that is not operationally defined in the same way, across studies (Lipsey & Wilson, 2001). This effect size measure is also used where the groups are not experimentally defined (Lipsey & Wilson, 2001) as in this review where race was the definition of group. This measure is known as *d* or Cohen's *d*. The primary formula for the calculation of the most precise estimate (Hedges & Olkin, 1985) of S M D is:

(1)

$$d = \frac{\bar{x}_1 - \bar{x}_2}{S_{pooled}}$$

$$S_{pooled} = \sqrt{\frac{(n_1 - 1)S_1^2 + (n_2 - 1)S_2^2}{(n_1 - 1) + (n_2 - 1)}}$$

(Borenstein et al., 2009; Hedges & Olkin, 1985; Lipsey & Wilson, 2001, pp. 47–49)

Where $\bar{x}_1$, $\bar{x}_2$ are the respective means n_1, n_2, are the sample sizes of the two groups and S_1,S_2 are the standard distributions of the scores of the two groups. In all cases in this study Group 1 refers to African American identified participants and Group 2 to European American participants.

Hedges provided a correction for the bias this effect size shows on small sample sizes making the corrected formula:

(2)

$$g = \left[1 - \frac{3}{4N - 9}\right] d$$

(Borenstein et al., 2009; Hedges & Olkin, 1985; Lipsey & Wilson, 2001; Rosenthal, Rosnow, & Rubin, 1999)

N is the total sample size for both groups.

The associated Standard Error is:

(3)

$$SE_{sm} = \sqrt{\frac{n_1 + n_2}{n_1 n_2} + \frac{g^2}{2(n_1 + n_2)}}$$

The Inverse variance weight formula is:

(4)

$$w_{sm} = \frac{1}{SE_{sm}^2} = \frac{2n_1 n_2(n_1+n_2)}{2(n_1+n_2)^2+n_1 n_2 g^2}$$

(Lipsey & Wilson, 2001)

It is not uncommon in the reporting of studies that information that would be used in the above formulas is not reported directly (Cooper, 2009; Lipsey & Wilson, 2001; Pigott, 2009). There are a number of alternative formulae available to convert alternate reporting of study results to an estimated SMD. Table 11 lists the data required to calculate the effect size for different reporting data types and the appropriate formula. An effect size calculator based on these formulae is available on the George Mason University website (D. B. Wilson, 2010c) or on the Campbell Collaboration website (D. B. Wilson, 2010a) and was used to facilitate calculation of appropriate effect sizes.

Table 11

Formulae for Additional Transformation to SMD

Transform for SMD	data required	Formula	ref Lipsey and Wilson, (2001)
Means and Standard Deviations	Mean, Standard Deviation, Sample Size	$d = \frac{\bar{x}_1 - \bar{x}_2}{S_{pooled}}$	p.198
T-Test, Unequal Sample Sizes	Sample Size (n) Treatment and control, t-value	$ES_{am} = t\sqrt{\frac{n_1 + n_2}{n_1 n_1}}$	p.198
T-Test, Equal Sample Sizes	Total Sample Size, t-value(assumes equal sample sizes for groups)	$ES_{am} = \frac{2t}{\sqrt{N}}$	p.198
F-Test, 2-Group, Unequal Sample Sizes	Treatment group sample size (n),Control group sample size (n),F-test (2 group, one way)	$\lvert ES_{am} \rvert = \sqrt{\frac{F(n_1 + n_2)}{n_1 n_2}}$	p.199
F-Test, 2-Group, Equal Sample Sizes	Total Sample Size(assumes equal sample sizes for groups),F-test (2 groups, one way)	$\lvert ES_{am} \rvert = 2\sqrt{\frac{F}{N}}$	p.199
T-Test P-Value, Equal Sample Sizes	Sample Size (n) (assumes equal groups), p-value of t-test	From tables e.g. Lipsey & Wilson (2001, p. 203) determine *t* from *p* and *df* then use *t*-test	p.199
T-Test P-Value, Unequal Sample Sizes	Treatment group sample size (n),Control group sample size (n),p-value of t-test	From tables e.g. Lipsey & Wilson (2001, p. 203) determine *t* from *p* and *df* then use *t*-test	p.199

Transform for SMD	data required	Formula	ref Lipsey and Wilson, (2001)
Means and Standard Errors	Mean, Standard Error, Sample (n) for treatment and control groups	$s = se\sqrt{n-1}$	p.200
2 by 2 Frequency Table	Outcome frequency of yes/no for treatment and control. Decide method Logit, Cox Logit or Probit.	$ES_{sm} = ln\left(\frac{ad}{bc}\right)\frac{\sqrt{3}}{\pi}$	Wilson, 2011
Binary Proportions	Proportion with event and sample size for both treatment and control	$ES_{sm} = probit(p_1) - probit(p_2)$ probit transformation of *p* Lipsey & Wilson (2001, p. 20	p.200
Point-Biserial Correlation	Sample size (n) (treatment and control), Point-Biserial r	$ES_{sm} = \frac{r_{pb}}{\sqrt{p(1-p)(1-r^2)}}$ r_{pb} is correlation coefficient *p* is proportion of subjects in group 1	p. 68
Point-Biserial Correlation Equal groups	Total Sample size(assume n1=n2), p-value Point-Biserial r	$ES_{sm} = \frac{2r}{\sqrt{1-r^2}}$	p. 178
Point-Biserial Correlation P-Value, Equal Ns	Total Sample size(assume n1=n2), p-value Point-Biserial r	Transformation available in calculator, Equation not available.	

Transform for SMD	data required	Formula	ref Lipsey and Wilson, (2001)
Point-Biserial Correlation P-Value, Unequal Ns	Sample size (n) (treatment and control), p-value Point-Biserial r	Transformation available in calculator, Equation not available.	
Phi-Coefficient	Phi-Coefficient (r from 2x2), sample size (Note: use 2x2 frequencies or binary proportions if available)	$ES_{sm} = \frac{2r}{\sqrt{1-r^2}}$	p.200
Phi-Coefficient P-Value	p-value (Phi-Coefficient (r from 2x2)), sample size (Note: use 2x2 frequencies or binary proportions if available)	Transformation available in calculator, Equation not available. Low likelihood of use	
Chi-Square	Chi squared from 2x2, sample size (Note: use 2x2 frequencies or binary proportions if available)	$\lvert ES_{sm} \rvert = 2\sqrt{\frac{\chi^2}{N-\chi^2}}$	p.200
Chi-Square P-Value	p- value of Chi squared from 2x2, sample size (Note: use 2x2 frequencies or binary proportions if available)	Transformation available in calculator, Equation not available. Low likelihood of use	
Frequency Distribution	Each group's frequencies on an ordinal or better scale	(f) frequency counts(i) each level (x) variable $\bar{x} = \frac{\sum x_i f_i}{\sum f_i}$ $s = \sqrt{\frac{(\sum f_i)(\sum x_i^2 f_i) - (\sum x_i f_i)^2}{(\sum f_i)^2}}$	p.199

Transform for SMD	data required	Formula	ref Lipsey and Wilson, (2001)
Means and Full Sample Standard Deviation	Full sample SD, Mean, N(treatment and control)	$S_{pooled} = \sqrt{\frac{s^2(N-1) - \frac{(\bar{x}_1^2 + \bar{x}_2^2 - 2\bar{x}_1\bar{x}_2)(n_1 n_2)}{n_1 + n_2}}{N-1}}$	p.199
F-Test, 3 or More Groups	F-value(one way), Type of group(treatment, control, other) Mean, N.	(k) groups, F-ratio (F), mean for each group ( ), sample size(n), for each group (j) $S_{pooled} = \sqrt{\frac{MS_b}{F_{oneway}}}$ $MS_b = \frac{\Sigma n_j \bar{x}_j^2 - \frac{(\Sigma n_j \bar{x}_j)^2}{\Sigma n_j}}{k-1}$	p. 200
Means and ANCOVA	MS error, Correlation (covariate with DV), Mean, *N* (treatment/control)	$S_{pooled} = \sqrt{\left(\frac{MS_{error}}{1-r^2}\right)\left(\frac{df_{error}-1}{df_{error}-2}\right)}$	p.200

According to Lipsey and Wilson (2001, p. 50) there is a degree of approximation as the data provided ranges from complete descriptive data through t-tests, and the statistics associated with a one way ANOVA. However, even though these are all estimates they do allow comparison across studies (Borenstein et al., 2009; Cooper, 2009; Lipsey & Wilson, 2001).

Where there was not sufficient data to calculate an effect size, the report entered the missing data process and attempts were made to contact the author and retrieve sufficient data. If the data was not retrieved, the report was discarded and cause recorded.

Documenting the Process

Initial code pages. The code pages are provided in the Appendix A. As expected, these code pages were updated and modified during coding of the pilot studies.

Coding database. Excel was used as the data repository for both coding and logging of process steps. The analysis and reporting was done with Excel extensions (Neyeloff et al., 2012). The design for the coding database was completed during the initial coding pilot. This spreadsheet is available on request and is not included with this report.

Bibliographic database. The bibliographic database is the repository of the links to the studies and contains identifying information, the assignment of the tracking Study ID, and the include/exclude decision information. Zotero was be used for citation and access management. Documents of the coding process and the database of studies sampled are available on request.

Process log. As part of the overall level of documentation required for the meta-analysis, a log of processing was kept in an excel Database. Appendix A contains supporting documentation for the search, coding and analysis processes. The working excel spreadsheets are available on request but could not be attached to this report.

Analysis

The process of meta-analysis to this point has been to select studies that can be compared meaningfully at a conceptual level (Lipsey & Wilson, 2001, p. 2) and that have statistics that can be standardized for comparison (Borenstein et al., 2009; Lipsey & Wilson, 2001). The purpose of the Analysis phase of the meta-analysis is to take all of

the coded data from the different studies and prepare the results for interpretation. It is this standardization of the study findings into a quantitative form that allows interpretation consistently across the studies (Lipsey & Wilson, 2001, p. 4).

Random or Fixed Effect Model

The fixed effect model assumes that the difference observed in the sample of effect sizes is entirely due to sampling error (Borenstein et al., 2009; DeCoster, 2004). In the random effects model there are considered to be two sources of variation, the sampling error in the studies and the random variation that occurs because the effect sizes are drawn from a population of effect sizes (Borenstein et al., 2009; Hedges, 2009; D. B. Wilson, 2011b). If inferences outside of the set of studies in the model are required, then a random effect model is used (DeCoster, 2004; Ellis, 2010). In this meta-analysis the random effects model was selected, as many different instruments are used to measure the construct, and therefore a population of effect sizes would be expected to exist. The random effects model is appropriate in most meta-analysis (Ellis, 2010, p. 129) and was the appropriate choice for this review.

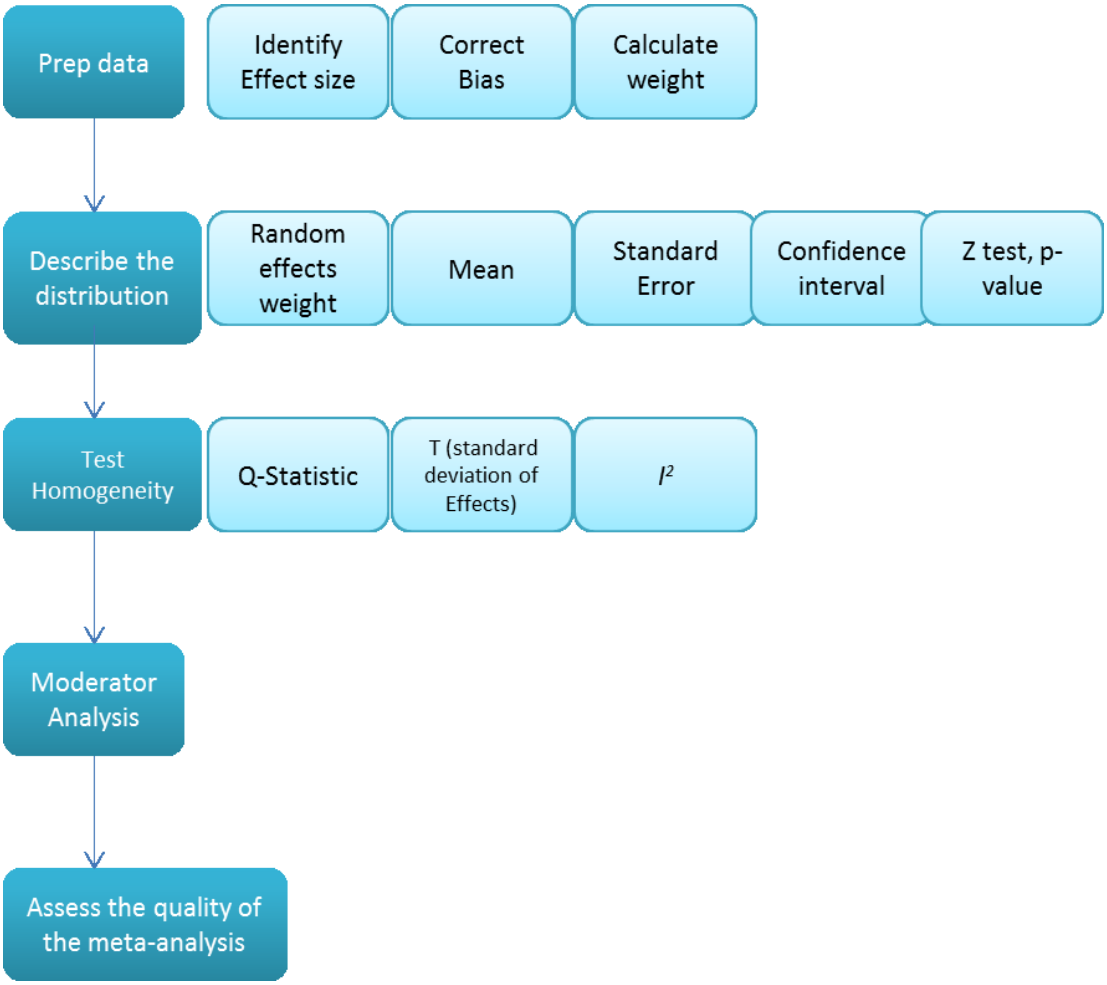

Figure 5. Meta-analysis (inverse variance weighted) processes.

Preparation of Data

Meta-analysis assumes the independence of data (Lipsey & Wilson, 2001) which has the consequence that only one effect size for a study can be used in a meta-analysis (Lipsey & Wilson, 2001). The first part of the preparation of data was to identify the effect size that was used from each study (D. B. Wilson, 2011b).

All effect sizes available during coding had the bias correction for small sample sizes applied, and the calculation of the standard error and the inverse variance calculated

(Lipsey & Wilson, 2001). The inverse variance weight was used during the analysis to ensure that studies that had larger sample sizes had a greater contribution to the outcome than those with small sample sizes (Borenstein et al., 2009; Lipsey & Wilson, 2001).

Describing the Distribution of the Effect Size

Once an independent subset of effect sizes (Borenstein et al., 2009; D. B. Wilson, 2011b) has been compiled and the unbiased preparatory calculations are done (Borenstein et al., 2009; Cooper, 2009; Lipsey & Wilson, 2001; D. B. Wilson, 2010a), the description of the distribution of the effect sizes is calculated. The mean of the effects is calculated, and the precision measures of standard error, confidence intervals, and the z-score and associated p-value (Borenstein et al., 2009; Cooper, 2009; Lipsey & Wilson, 2001). In practice, the calculations were done using Excel with extensions (Neyeloff et al., 2012). But the calculations are possible without a computer using the following formulae.

Using the Random effects model requires the computation an estimate of the random effects variance component T^2 (Borenstein et al., 2009; Lipsey & Wilson, 2001) which is an estimate from the observed effects of τ^2, the variance of the true effect sizes (Borenstein et al., 2009). The following formulas are used to calculate T^2:

(5)

$$T^2 = \frac{Q - df}{C}$$

(6)

Where df = k – 1

(7)

$$C = \sum w_i \frac{\sum w_i^2}{\sum w_i}$$

This allows the recalculation of the weights to be used in the meta-analytic computations.

(8)

$$w_i = \frac{1}{se_i^2 + T^2}$$

The statistics that describe the distribution can now be calculated using the random effect model (Borenstein et al., 2009; Lipsey & Wilson, 2001)

(9)

$$M_{ES} = \frac{\sum_{i=1}^{k} w_i ES_i}{\sum_{i=1}^{k} w_i}$$

Where M_{ES} is the meta-analytic mean effect

w_i is the inverse variance with an estimate of the random effects variance

ES_i is the effect size of the study

k is the number of studies

i is each study

The standard error of the mean effect size is:

(10)

$$se_{M_{ES}} = \frac{1}{\sum_{i=1}^{k} w_1}$$

The confidence interval at the .05 significance level can be calculated by:

(11)

$$M_{ES_{lower}} = M_{ES} - se_{M_{es}} 1.96$$

The *z*-score to test the null hypotheses that the mean effect is zero can be calculated using:

(12)

$$z = \frac{M_{ES}}{se_{M_{ES}}}$$

The associated *p* values are available in tabular form but can also be calculated in Excel using the =NORMSDIST(Z*) formula. For this analysis Excel with extensions (Neyeloff et al., 2012) was used for calculations.

Finding the True Effect Size of the Analysis

The random effects model for the meta-analysis was chosen because the studies could not be assumed to be "functionally equivalent" (Borenstein et al., 2009, p. 83), and that the assumption that the studies were all representative of the same population and that the effect sizes was homogenous, was false (Lipsey & Wilson, 2001). Using the random effects model was based on the assumption that the observed effect sizes in the studies would include both the true variance in the effect sizes and random error (Borenstein et al., 2009). The term "heterogeneity" was used following Borenstein et al. (2009) to refer to the distribution in the true effect variance component only. To allow interpretation of the results of the meta-analysis it is necessary to describe the evidence of

heterogeneity in true effect sizes and the variance. The meaning of the dispersion in the context of the study, as well as how much of the effect size seen is real rather than what can be attributed to random error (Borenstein et al., 2009), can be described.

To interpret the outcome of the meta-analysis using the random effect model, the true-between-studies variation was required not the observed variation. This required finding the total study to study variation. Then I made an estimate of what the study to study variation would be assuming there was no difference in the real effects. The difference between the two indicates the real variance or heterogeneity (Borenstein et al., 2009).

This first step in the process was to test the assumption that the effect sizes were estimating the population mean (Lipsey & Wilson, 2001) and to gain insight into the dispersion of the observations (Borenstein et al., 2009). When homogeneity was rejected I could assume that there were real differences between the studies that were not explained by sampling error, and that they were drawing from different populations (Lipsey & Wilson, 2001). The statistic Q was used to test homogeneity calculated as follows:

(13)

$$q = \sum_{i=1}^{k} w_i (ES_i - M_{ES})^2$$

In essence the difference of each effect size from the mean was calculated, squared and weighted by the inverse variance for the study. These values were summed

over all studies to give a weighted sum of squares or Q, a standardized measure that is not impacted by the metric used for the effect size (Borenstein et al., 2009). The Q statistic is not an estimation of the size of the true differences amongst the effect sizes but rather an estimation of the study to study variation (Borenstein et al., 2009).

The expected value of Q if there is no difference in the true effect size from study to study is the degrees of freedom of the study

(14)

$$df = k - 1$$

and the component of the variation that can be attributed to variances in the true effects is:

(15)

$$Q - df$$

(Borenstein et al., 2009, p. 110)

Because Q follows a central Chi-squared distribution with degrees of freedom equal to k-1 (where k is the number of effect sizes) the p- value of Q can be reported (Borenstein et al., 2009). Alpha was set at 0.05 for this review, and a p-value less than alpha caused a rejection of the null hypothesis and an assessment that the studies do not share a common population (Borenstein et al., 2009; Lipsey & Wilson, 2001). Where there are a small number of studies included and small sample sizes in the study the Q statistic is underpowered and may cause an invalid failure to reject the null hypothesis (D. B. Wilson, 2011b).

The true effect sizes cannot be observed, so the variance cannot be directly computed, however an estimate T^2 can be made where

(16)

$$T^2 = \frac{Q - df}{C}$$

and the dispersion can be understood in the same scale as the effect size by calculating the estimated standard deviation T (Borenstein et al., 2009). If Q< df then T^2 is set to 0 as it is not possible to have a negative variance (D. B. Wilson, 2011b), and if Q> df the T^2 is positive and

(17)

$$T = \sqrt{T^2}$$

In a similar way to the standard deviation in primary research, T can be used to describe the distribution of the effect sizes about the mean (Borenstein et al., 2009). T gives a greater understanding of the range of the true effects about the mean. If T is small there is a relatively limited range of values for the true mean, if T is larger the range of values within which the true mean falls is much larger.

To facilitate understanding and interpretation of results, and to overcome the known Q bias of poor detection of heterogeneity in an analysis where there is a small number of studies, and a bias towards excessive power with large numbers of studies, Higgins I^2 is calculated (Higgins, Thompson, Deeks, & Altman, 2003). The Higgins I^2 statistic "quantifies the effect of heterogeneity, providing a measure of the degree of

inconsistency in the studies' results" (Higgins et al., 2003). The I^2 statistic helps to see what part of the variance observed is the real difference in effects size providing a view of how much of the total variance is the true difference. The I^2 statistic is a descriptive statistic (Borenstein et al., 2009) that is an indication of the level of inconsistency between the studies and not a measure of the real variation (Borenstein et al., 2009). It can be used to indicate if there is a need to explain the variance. If I^2 is small then it is reasonable to assume that the variation is an artifact of the analysis. If I^2 is medium to large (>50-75%) (Higgins & Thompson, 2002; D. B. Wilson, 2011b) then additional analysis is appropriate. For example, where there is a large inconsistency it would be appropriate to break the studies into subgroups to try to assess where the inconsistency lies. In this study, it was expected that one of the subgroups would be the different instruments that were used, and in fact the most productive analysis was at this level. I^2 is calculated with the following formula:

(18)

$$I^2 = \left(\frac{Q - df}{Q}\right) \times 100\%$$

Or alternatively if required in the effect size metric rather than standardized form.

(19)

$$I^2 = \frac{T^2}{T^2 - \sigma^2}$$

While formulae exist for the calculation of confidence intervals for I^2, the recommendation is to use I^2 as a descriptive statistic to supplement Q as the sampling

distribution is derived from the sampling distribution of Q and therefore the power characteristics will be the same as Q (Shadish & Haddock, 2009, p. 263). Negative values of I^2 are set to zero, with possible values ranging from 0-100%.

Graphical Methods

There are several graphical methods of displaying results from a meta-analysis that can assist in the interpretation as well as the presentation of the findings. The L'Abbé plot is used in meta-analysis to show variations in observed results that are plotted with the event rate in the treatment group on the vertical axis and that in the control group in the horizontal axis (Song, 1999). This study was not a meta-analysis of clinical trials but rather of survey type studies so there was no reason to use a L'Abbé plot. A scatter plot of the studies referred to as a funnel plot of sample size is plotted on the vertical axis and the standardized effect size is plotted on the horizontal axis (Higgins & Green, 2011). This provides another alternative way of looking at the different studies, but again because of the size of the sample was not realistic for this study. The forest plot is "the new standard for the presentation of meta-analytical findings" (Borman & Grigg, 2009, p. 505), although it is less used in the social sciences. The Campbell Collaboration often includes the forest plot, but it is not universal (Borman & Grigg, 2009). The forest plot uses text and graphics to display the sample size, the effect size, and the confidence intervals of the studies included in the analysis, and to present a summary effect size for the whole analysis.

As with primary studies, in the random effects model for meta-analysis, both the mean effect size and the distribution of the true effects about that mean (Borenstein et al.,

2009) are important. The confidence interval is the quantification of the accuracy of the mean.

When produced on a forest plot like the example below, the horizontal line though each point is the confidence interval associated with that study, the solid vertical line with a diamond represents the mean of the analysis. In this example the mean for comparable population norms is also plotted (in a dotted vertical line) for comparison. In this analysis the meta-analysis and forest plots in the results section and in Appendix A were developed using Microsoft excel extensions (Neyeloff et al., 2012)

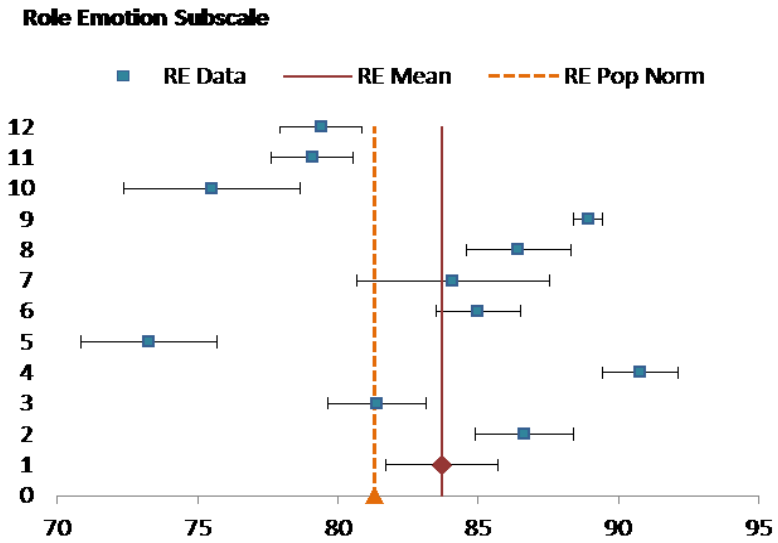

Figure 6. Example of a forest plot

Note: showing the effect and confidence intervals for studies included and the summary effect for a subscale of data from SF-36 data Calculated using the excel extensions in Neyeloff et al., 2012, p. 4 which is licensed under a Creative Common license Attribution 3.0 Unported (CC BY 3.0)

Moderator Analysis

Moderator or subgroup analysis allows for a greater understanding of the variation in the mean effects seen in the studies that makeup the meta-analysis. The first step in understanding the variance is to compare the mean effects for studies that fall into different subgroups (this is like using an analysis of variance in primary research) (Borenstein et al., 2009). When this comparison is done it can be followed by assessing the relationship between the covariates from study to study in a process analogous to multiple regression in primary studies (Borenstein et al., 2009; Cooper, 2009). This assessment is done in an attempt to gain an understanding of the variability in the distribution of effect size estimates (Ellis, 2010).

Multiple moderator analyses were planned. The first analysis that was planned was of the categorical moderator of the measurement instrument. An analogue if the ANOVA procedures using code for SPSS (D. B. Wilson, 2010b) was planned to be used to perform the moderator analyses as all were categorical variables. Looking at the variance in effects from one instrument to another would have allowed for an indication if the instruments impact the effect size. For example, does measuring HRQOL using a FACT – B, instrument have a significantly different mean effect than if the EORTC QLQ-C30- BR-23 were used? Looking at the studies grouped by those that used multiple instruments and those that used more comprehensive instruments to see if there was a significant difference in mean effects also had the potential to shed light on the impact of the instrument. Unfortunately, the number of studies available meant that the moderator analysis was not possible, and the comparison across instruments severely limited.

It was planned that if during coding of studies data on SES and age were sufficiently reported in the studies a moderator analysis would also be executed. For example, if age were coded in enough studies to allow subgroups of studies and effect to be identified, the analysis may have shown differences in HRQOL for women of different ages. Variables associated with study methodology, location and approach, and recruitment and administration approach were also slated to undergo moderator analysis to understand if methodological questions had a significant effect on the findings. For example did studies that were done in single facilities show a difference in HRQOL mean effect to those that were population based. Finally, a subgrouping of studies by HRQOL component was planned, to try to add dimension to the outcome of the overall analysis by finding if there were differences at the component level of the studies. None of these analyses was possible during the study because of insufficient data.

Understanding the Quality of the Meta-analysis

There is a bias towards statistically significant studies in published research (Ellis, 2010; Lipsey & Wilson, 2001). This bias means that a "fail safe" *N*, or the number of studies that have conflicting evidence that would need to be included to overturn the result (Ellis, 2010), should be calculated to understand how likely it is that there is a false positive in the meta- analysis. This calculation was not performed as the population size was too small to complete the meta-analysis.

Calculating the power of the analysis. The statistical power of the random effects model approach to meta-analysis is impacted by both the within studies and

between studies variance (Borenstein et al., 2010). To facilitate interpretation the calculation of the statistical power of the study was planned.

An analysis of the impact of removing all studies where there was a power level less than .50 was planned to see the impact that low powered individual studies had on the overall analysis (Ellis, 2010, p. 127), but proved unnecessary.

Presenting the results of the analysis. The PRISMA guidelines (Moher et al., 2009) were used as guidance in the presentation of the material with modifications to comply with the required Walden template. This format supports the presentation of how the effects were distributed (Cooper, 2009; DeCoster, 2004), why moderator analysis was done and what was found, and the correlations between moderators and regression models used (DeCoster, 2004).

Information about the included studies and the outcome of the meta-analysis was presented in the form of a forest plot (Borenstein et al., 2009; Cooper, 2009; DeCoster, 2004; Ellis, 2010; Lipsey & Wilson, 2001), with a discussion of outliers and the possible underlying dispersion (DeCoster, 2004). Information on the total number of participants (DeCoster, 2004), and the number of participants in the different race/ethnic categories (DeCoster, 2004; Lipsey & Wilson, 2001) was provided for the different analyses performed. The mean weighted effect sizes with their confidence intervals from the different studies were presented in the forest plots, (Lipsey & Wilson, 2001, p. 144), and the corresponding heterogeneity results are noted (DeCoster, 2004).

At the very least in this study, a subgroup analysis of the different instruments used was planned to be conducted and presented. Multiple Regression is used in primary

studies to allow the assessment of the relationship between "one or more covariates (moderators) and the dependent variable" (Borenstein et al., 2009). An analogous process is available for meta-analysis that allows for the assessment of the relationship of the study level moderators and the study level effect sizes (Borenstein et al., 2009). Software used to do this must be specifically designed for Meta-regression to ensure that the study weights and meta- analysis model can be correctly assigned (D. B. Wilson, 2011a). On the completion of coding, it was understood that there was not sufficient data to complete moderator analysis so a meta- regression was not required.

Interpretation of the results. In published journals there is a growing requirement for the interpretation of results of a meta-analysis to contribute to a greater depth of understanding of theory (DeCoster, 2004; Ellis, 2010), or ensure that the findings are reported in plain language, driven according to Ellis (2010) by journal editors requiring that a deeper level of interpretation be provided. Interpretations should take the bare statistics and provide a practical statement of what the findings mean in relation to who may be affected, and any consequences of the more comprehensive knowledge that is provided by the analysis (Ellis, 2010; Lipsey & Wilson, 2001)

The interpretation section should also deal with any issues with the study, and any implications for future research (DeCoster, 2004; Ellis, 2010; Lipsey & Wilson, 2001). There are a number of criticisms of the process of meta-analysis that must be incorporated in the interpretation and discussion of results. One of the criticisms of meta-analysis is that when the studies are combined, especially when they are not simply replications of each other, it is like trying to combine apples and oranges (Borenstein et

al., 2009; Lipsey & Wilson, 2001). Rosenthal said that "combining apples and oranges makes sense if your goal is to produce fruit salad" (Rosenthal in Borenstein et al., 2009, p. 357). Part of the goal of the interpretation section is to make sense of the "fruit salad" that is the outcome of a meta-analysis, and to be able to explain why logically the studies that were put together make sense.

Often the goal of a meta-analysis, as it was in this study, is to broaden understanding by looking at research with a different lens (Borenstein et al., 2009). The interpretation of the findings is not necessarily that a common significant effect has been found, but rather an understanding of the dispersion in effects and what that can tell us about the body of knowledge is also important. While the meta-analytic approach was criticized early for using a single number to describe the body of knowledge under study (Borenstein et al., 2009), the interpretation of the outcome of the meta-analysis requires more than a single answer. If there is a dispersion of effects, how big is that dispersion and where is it noted is just as important in the conclusions that are reached about the analysis.

This methodology assumes the likely hood of publication bias (Borenstein et al., 2009; Cooper, 2009) where studies that had null or negative findings might not have been reported or published, and that important studies might have been missed (Lipsey & Wilson, 2001). The assumption can be made that not all studies that were relevant were uncovered, and it is not possible to even know what has been missed. Thoughtful consideration and open process and documentation at least allow for transparency of the approach and interpretation (Borenstein et al., 2009; DeCoster, 2004; Lipsey & Wilson,

2001). Not all studies that are included in a meta-analysis are perfect. However, studies that are methodologically suspect, or that are of low power may still have value in the overall understanding of the question. Identifying why studies were included and excluded for all reasons in this study was an attempt to overcome the "garbage in-garbage out" (DeCoster, 2004, p. 3) criticism that has been leveled at meta-analysis (Ellis, 2010).

The visibility of the process is a component of the interpretation and is part of the presentation of the research in an attempt to make finding a poor analysis easier that with other forms of aggregation (Cooper et al., 2009; Cooper, 2009; Lipsey & Wilson, 2001). The interpretation of the findings will always be impacted by the inability to include all possible studies, by the decisions made during the data collection and coding, and by research questions that began the process. An open and meticulously documented process that provides clear and open access to decisions made is the best way of ensuring that the interpretations of the data can be openly checked and tested.

Ellis (2010, p. 3) asked the question "So what? Why do this study?" Meta-analysis requires the investment of significant effort (Lipsey & Wilson, 2001); within the interpretation of the findings is where context and language that is meaningful to non-researchers is used. Chapter 5 of this report is where the context of what I found is discussed.

Documentation

Part of the value of meta-analysis lies in the openness with which the process is documented and the thoroughness with which records of the analysis are kept (Borenstein

et al., 2009; Cooper, 2009; DeCoster, 2004; Ellis, 2010; Lipsey & Wilson, 2001). This thorough recording inevitably leads to a large volume of documentation. The organization of the data and the meticulous keeping of records require the use of electronic storage. Unless specifically required, no hardcopy of the documentation is planned. Excel spreadsheet documentation of this process, while not included with the text of this dissertation, is available and will be retained for a minimum of 5 years.

Electronic storage has some important advantages for storage of documents. It is easier to disseminate even large documents, and storing multiple copies in various locations means that it is easier to protect against total loss of the document. However, there are some negative characteristics of electronic storage that must be addressed.

The ease with which an electronic document can be destroyed by accident or on purpose is an important consideration. Fortunately, a good backup plan with data stored in multiple physical and virtual locations can alleviate that problem. This document will be stored with a multiple stage backup on a personal computer, a network server, in physical offsite storage, and in an online storage vault. Because magnetic media can degrade over time, the media will be refreshed at least annually for5 years, at which time an evaluation will be made of the need to continue that practice.

Documents stored electronically are much more malleable than hard copy documents if stored in a form that is easily updatable. There is a trade off in being able to copy parts of a document and in keeping it pristine. The documents associated with this study will be stored in Portable Data Format (PDF) a fixed form stable content document version that is difficult to change. As spreadsheets cannot be easily stored as PDF, a

password protected form of the spreadsheets will also be saved. All documents will be stored with a digital signature to increase the protection. A backup of the malleable form of the document will be kept, password protected, should the PDF ever have to be recreated, and should the creating program be upgraded before the decision is made to discard the malleable form, the document will be upgraded to readable by the new version.

One of the issues with electronic storage is finding the document. The PDF form and password protected form will be stored with keyword and citation metadata to facilitate retrieval and file naming conventions that include author, date and key content information will be used.

There are three concerns when one is using electronic document storage. These concerns are related to making sure that the content is adequately preserved, making sure that the storage media is robust enough to maintain integrity, and ensuring that metadata is stored with the document so that the context of the document and its sources are easily searchable. The storage and backup plans for this document address all of those concerns.

Protection of Human Participants

As this study was a meta-analysis, there were no human participants in the study.

Dissemination of Findings

The final report of the study will be presented for evaluation by the committee members. Publication of findings will be evaluated at the time it is accepted.

Summary

The design for this study was for a meta-analysis based on the SMD effect size planned to be calculated between the data for African American survivors and European American survivors. HRQOL as measured by standard instruments was the dependent variable, and it was planned that covariates of the instrument used, and if data were available socio-economic status and age. A search of electronic databases was planned and executed and the candidate studies processed through coding and analysis.

Chapter 4 presents the results of the process beginning with a summary of what was found and providing detail of key components of the outcome. More detail of results is available in Appendix A.

Chapter 4: Results

Overview

After conducting an electronic search for articles that included studies where the population studied was of women who had been diagnosed with early-stage breast cancer more than 5 years previously, and where the HRQOL was a dependent variable, 56 peer-reviewed articles, dissertations, or reports were entered in the initial coding phase of the study.

The coding phase of the study included articles that examined HRQOL measured on standard instruments, where more than one study used an instrument and where enough data were provided for either the calculation of SMD or where mean and standard deviation were provided. Only reports that were based on a U.S. population and included participants of either African American or European American racial identification were included, resulting in the inclusion of 22 reports in the final meta and comparative analysis. Following the research method of strict meta-analysis, one study allowed for the calculation of an effect size of the difference between African American and European American population HRQOL. The percentage of African American participants was lower in the 22 studies in the analysis phase than in the BCS population in general. Nine studies did not report racial breakup of participants and few reported the data for African American and European American populations separately.

African Americans, when compared to European Americans, showed a negative SMD effect size. There was not enough data to calculate the effect size as in other meta-analyses.

I then turned to the question of HRQOL as operationalized in the MOS SF-36 (also referred to as *SF-36*). The SF-36 instrument has been used in both healthy and clinical populations and in both cross sectional and longitudinal studies (Zebrack, 2004). It is a standardized, general measure of health status with normative data available from the United States population, but not for different racial backgrounds, and is used in oncology populations including breast cancer (Zebrack, 2004). It includes the HRQOL dimensions of physical, mental, and social quality of life and is the most evaluated HRQOL measure across numerous patient populations (Garratt, Schmidt, Mackintosh, & Fitzpatrick, 2002).

I conducted an analysis of the results from 13 studies that used the SF-36 to measure HRQOL. SMD no greater than 0.07 (i.e. no greater probability than chance) were found between the total population of long-term breast cancer patients (including both African American and European American participants) and SF-36 population norms (1990) for the summary scales of this instrument (Physical Component Scale [PCS] and Mental Component Scale [MCS]), and in the subscales of the instruments that report on the separate dimensions of HRQOL.

Insufficient data meant that it was not possible to draw conclusion as to the impact of race on the scoring across the subscales. One study (Chen, 2005) was the only study that reported subscale data using the SF-36 for African American (n = 101) and European American women (n = 3,150) separately. Chen's (2005) dissertation was a study of women 5 years post breast cancer from registry data, and it included both Canadian and U.S. participants, but only the U.S. data were analyzed for my study in

keeping with the criteria set for inclusion. African American women scored lower on all subscales, with an effect size in the low to moderate range.

The small number of studies that used either the QOL-CS or the Quality of Life Index – Cancer Version III (QLI-CVIII) instruments, as well as the lack of population norms available for those instruments, meant that few conclusions could be drawn about the usefulness of those instruments in this study.

Research Questions

1. Compare the effects of survival for more than 5 years post treatment on HRQOL of African American breast cancer patients diagnosed with Stages 0-II with those of patients of European American racial identification.

Three studies contained a direct comparison of data from African American and European American participants. While a meta-analysis theoretically only requires a minimum of two studies (Lipsey & Wilson, 2001), only one study had data that were at an overall HRQOL level, and two of the studies provided data on different categories and subscales. Some data analysis was possible to suggest direction and size of effect.

2. Is enough data available in the population of studies to observe the impact of age on the effect size?

The moderator variable of age could not be assessed due to insufficient data to calculate effect size.

3. Is there enough data on SES in the population of studies to identify its impact as a moderating variable?

The moderator variable of SES could not be assessed due to insufficient data to calculate the effect size.

4. Can the choice of HRQOL instruments be identified as having an impact on the effect size seen in the research?

Separate analysis was done of the data from the different instruments identified in the studies and those data are presented.

5. Can subgroup analysis identify differences in components of HRQOL?

Component parts of HRQOL could not be assessed in the population because there was not enough data to evaluate the effect size. For the SF-36 instruments, subscale comparisons to population norms were conducted.

6. The null hypothesis for the study is that the mean effect size is zero (random effects model; Borenstein et al., 2010).

A full meta-analysis could not be performed, so the null hypothesis was neither supported nor unsupported.

The primary result of this study was that I was unable to complete the meta-analysis as originally planned. As a consequence, neither the secondary or tertiary questions could be answered. A summary of the data available was completed for those studies where an indirect comparison could be made.

This status was identified at the completion of the search phase of the study. Studies that met all criteria except those needed to make the comparison were coded and an analysis performed to identify if there was a difference in studies to attempt to answer the fourth research question. It was possible to do a subscale analysis of the most used of

the HRQOL instruments (SF-36) and some indication of overall comparison to population norms was possible, so the fifth question could be partially answered.

Process

As part of the search for and acquisition of copies of the studies, exclusion criteria were applied. At that point, it was identified that only one study included enough data. The decision was made to continue to code the studies to enable comparison of the instruments and an analysis of the data on participation in the studies. At the completion of coding, ad hoc analysis of the sources was conducted. In keeping with the process of meta-analysis, a meticulous accounting of the processes was kept and is available in soft copy. Appendix A includes addition information from the process.

Study Eligibility Criteria

Using an adaption from the Cochrane and Campbell Collaborations approach (Hammerstrøm et al., 2010; Lefebvre et al., 2011) and from Lipsey & Wilson, 2001(pp. 16–23) the study eligibility criteria used were set up before the search was initiated. During the search process, an additional criterion that excluded studies that had multinational populations but that failed to report their data separately was added to the eligibility criteria. The criteria in Table 12 were identified as a minimum for inclusion in a meta-analysis.

Table 12

Inclusion Criteria Used in Identifying Studies

Criterion	Status
Study must be quantitative in nature	All studies were quantitative in nature
Statistical findings must include sufficient information to transform to the effect size SMD	As mentioned in the introduction only one study provided data separately for African American and European American women. The calculation of SMD was not possible on more than one study so the meta-analysis failed.
Data of statistical outcomes must be available for at least a racial categorization of African American and European American or synonyms of those categorizations	While the racial categorization of African American and European American was used or identifiable in all studies statistical reporting was inadequate.
Racial classification must be that used by the American Cancer Society (2010, p. 4) or understandable in that context	All studies had appropriate racial classification.
Study must use one or more HRQOL instruments that were identified in this section or whose validity and reliability can be independently validated	Studies used HRQOL instruments identified in Table 13. Two studies were excluded from the final total because they were unique in their use of instrument.
Population must be clearly identified and preferably participant numbers identified	This criterion was met
Study must be in English	This criterion was met

Criterion	Status
Peer review is not a necessary criterion as it is possible that the "gray" literature including dissertations or government reports may have relevant study information. If a report is not peer reviewed it must be published under some authoritative body supervision	Dissertations were included in the final total. No government reports met the criteria.
Should a study meet all other criteria for inclusion but data is insufficient an attempt was be made to retrieve the needed data from the author before rejecting the study	For all study reports that otherwise met the criteria and where an author could be identified. Communication was attempted to recover the data to allow for the analysis. 47 authors were emailed. Two replied, neither has provided the data, although both expressed a willingness to do so. One of those authors proved to have a primarily non US participant base.

Two hundred and twelve studies were examined in full text using the criteria above. Of these 59 studies that appeared to meet the participant requirements and used standard identified quality of life measures, entered the coding phase. The following diagram (Fig 4.1) documents the search using the Preferred Reporting Items for Systematic reviews and Meta-Analysis (PRISMA) guidelines (Moher et al., 2009).

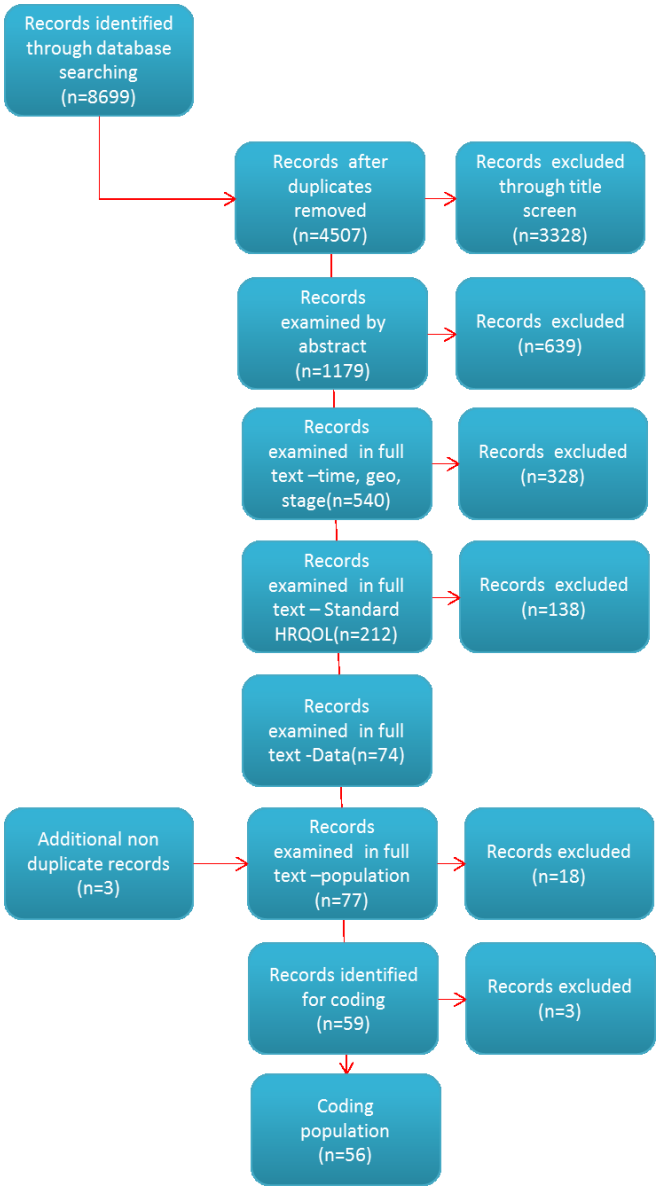

Figure 7. Search for reports of studies. Numbers returned from process steps and numbers excluded.

Note: Adapted from "Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement," by D. Moher, A. Liberati, J. Tetzlaff, D. G. Altman, and The PRISMA Group. (2009), *PLoS Med*, *6*(7), e1000097.

Coding Process

Of the 59 reports of studies that entered coding, 3 studies that used non-standardized measures were eliminated before entering coding and 34 were excluded during the process. Categories for the reason for exclusion were documented in Table 10. In some cases, multiple reasons applied but only the primary exclusion reason was documented.

Eleven studies were excluded based on study characteristics. Four studies did not fall within the population boundaries. Three of those were non-USA populations (Mosewich, Hadd, Crocker, & Zumbo, 2013; Muss et al., 2008; Zucca, Boyes, Linden, & Girgis, 2012). One (Clauser et al., 2008), was for a general cancer population that included Breast Cancer patients, but did not provide separate data for the BCS. Seven of the reports used non-standard HRQOL measures or were the only report to use a common measure (Boehmer, Glickman, Milton, & Winter, 2012; Caloudas, 2011; Mishel et al., 2005; Perkins et al., 2007; Porter et al., 2006; Von Ah, Russell, Storniolo, & Carpenter, 2009; Ziner, 2008)

Two studies were rejected based on the stage of cancer. Kornblith et al., (2003) did not delineate disease stage but identifies 22% of the sample experienced recurrence. In the other study rejected because stage was unclear (Reyes-Gibby, Anderson, Morrow, Shete, & Hassan, 2012), while only 13 of the 246 participants were identified as having Stage III Breast cancer, 5% were identified as having metastasis, 10% as having recurrence and 10% as having a new primary breast cancer. It was not clear from the report if those percentages were additive or refer to the same participants.

Thirteen of the reports of studies either had a mean years since diagnosis of less than 5 years or a large percentage (>20%) of the participants were less than5 years. In some cases, a few very long-term participants pulled the mean up to over 5 years but the majority of the participants were much closer to their diagnosis. Time since diagnosis has been shown to have an impact on HRQOL (Bloom, Stewart, Chang, & Banks, 2004; Ganz et al., 1996; Kessler, 2002). Setting the criteria to 5 years of disease free survival agrees with the commonly accepted time of transition into long-term survival (American Cancer Society, 2011). Reports that did not include a specification of time since diagnosis or where the time since diagnosis was biased towards those who had passed less than 5 years since diagnosis had potential to bias the results.

The final 11 reports that were rejected did not provide data that were usable in even the modified analysis that was executed. These reports fell into two major categories. The first category was where only results where significant statistical analysis were reported, or where the reporting was incomplete (Bloom et al., 2004; Bower et al., 2006; Paskett et al., 2008; Taylor et al., 2012). These may have been sufficient to support the study, but the data were not suitable for meta-analysis. The second category was more numerous and was where the author preprocessed data, adjusting them for age, time since diagnosis or for other variables that were the subject of that study (Ahmed, Prizment, Lazovich, Schmitz, & Folsom, 2008; Claus, Petruzella, Carter, & Kasl, 2006; Ganz et al., 2002; Ma, Carpenter, Sullivan-Halley, & Bernstein, 2011; Moy et al., 2006; Tomich & Helgeson, 2002; Von Ah et al., 2012). While the reporting described in these

reports supported the purposes of the studies, the reports were unusable for a meta-analytic study because there was not a clear indication of the transformation of the data.

Race as a Variable in Reports Rejected

Three of the reports that were primarily non-USA participants and were disregarded from any participant racial analysis (Mosewich et al., 2013; Muss et al., 2008; Zucca et al., 2012). Of the other rejected reports one (Moy et al., 2006; Tomich & Helgeson, 2002) reported only "Caucasian" participants, another only that there were n = 351 "minority" participants and n = 4708 Caucasian participants (Moy et al., 2006). This second was a report of the impact of a post breast cancer drug Letrozole on long-term quality of life and Disease Free Survival (DFS). The category identified as minority women did not see any change in disease free survival even thought there was a significant improvement for Caucasian women. In discussing the findings, the authors hypothesized that the "Large ethnic variations in allele frequencies and types in the aromatase gene between Caucasian Americans, African Americans, Han-Chinese and Mexican Americans" (Moy et al., 2006, p. 1640) could be contributing to variations in drug action observed. Moy goes on to point out treatment inequality, and overall cancer care may differ by patient race (Moy et al., 2006, p. 1641). While these comments were directed primarily toward drug action and treatment conditions, more granular reporting of HRQOL data would have been informative to the questions asked in this dissertation. HRQOL data changes were reported only at the level of Minority and Caucasian and then only in graph form.

Four of the rejected reports (Northouse et al., 1999; Rowley, 2000; Taylor et al., 2012; Von Ah et al., 2012) only had African American participants (total participants n = 307), and two reports (Ahmed et al., 2008; Bower et al., 2006) gave no breakdown of the participants in the studies. Several had either no identification of different minority participants or no African American participants (Heiney et al., 2013; Ma et al., 2011; Polinsky, 1994; Reyes-Gibby et al., 2012; Sammarco, 2009; Tomich & Helgeson, 2002). The total number of participants that could be identified in the rejected studies was n = 19,124 of who n = 17,359 had identification as African American, European American or other. Approximately n = 2268 of those identified were African American (13%), n = 14,044 (80 %) were European American, and n = 729 (6.3%) were identified as other minorities. These data were approximate as the reporting of actual racial statistics was not universal. Six instruments were used in the rejected studies as reported in Appendix A, Table A.4.

Summary Findings

The key question of the meta-analysis could not be answered. However, by using all of the data available and calculating SMD effect sizes for comparisons between African American and European American populations of studies, it was possible to develop and overview of the research.

Summary of effect sizes for African American and European American long term BCS studies

Study	Sample Size	Effect size SMD (95% CI)
QLI	326	-0.82(-1.06,-0.59)
Ashing Giwa, 1999	278	-1.46(-1.75,-1.17)
Summary	**604**	**-1.14 (-1.73,-0.54)**

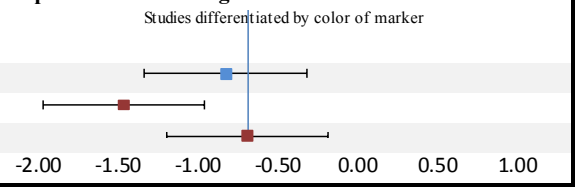

Figure 8. Summary of available effect sizes comparing African American and European American Long-term Breast Cancer patients using calculated SMD.

This forest plot summarizes the comparison of data derived from four different studies all of which used the same instrument the QLI-CV III. This included n = 124 African American participants (Huff, 2013; Leak et al., 2008) M= 22.75 SD= 5.07 and n = 202 primarily European American participants (Keating, 2007; Lee, 1997) was M= 27.25 SD=5.68. Giving a SMD of d = -0.8247 with 95% Confidence Interval (CI) of -1.0571 to -0.5923 v = 0.0141. This SMD would be considered a large effect size (Cohen, 1988) and would be expected to be observable in any of the social, economic or clinical contexts. The sample size of this comparison was small and alone would not be particularly useful as an overview of the impact. Q was significant for the fixed effect model, so the Random effect model was used. I^2 was of a moderate heterogeneity as expected when different measures were used.

While this was not a traditional way to achieve a SMD, combining studies that used the same instrument and therefore the same operational definition of HRQOL at least allows for an indication of differences that might be expected between long-term survivors of different ethnic backgrounds. The second component of this comparison was the one study where it was possible to estimate the SMD (Ashing-Giwa, 1999a; Ashing-Giwa, Ganz, & Petersen, 1999). The effect size was calculated from the

correlation coefficient and accounts for *n* = 117 African American participants and *n* = 161 European America participants with an effect size of –1.4615.

The total number of African American participants in this group was *n* = 241, and the total number of European American participants was *n* = 363. While the numbers of participants was relatively modest the ratio of African American to European American participants was high compared to the studies that entered into the coding phase. The reports that entered analysis had an African American Component of 8.1%, a European American component of 87.7% and other minority component of 4.8%. Nine reports did not identify racial breakdown of participants.

Additional indications of the direction of the difference between African American and European American long-term BCS can be seen in the study where no overall score on the SF-36 was available but where the information on the Physical Component Summary (PCS) and Mental Component Summary (MCS) scores was included (Trimble, 1997). The study was conducted with *n* = 21 African American participants and *n* = 205 European American participants and resulting in a negative PCS SMD effect size of -0.017 and MCS of - 0.322. The second would be considered a small effect size (Cohen, 1988) (both indicate that the African American participants scored lower than the European participants). The final study on which differences can be calculated (Chen, 2005), had a very large European American sample between *n* = 3115 and *n* = 3159 participants depending on the subscale of the SF-36 being reported and between *n* = 100 and *n* = 110 African American participants. The effect size for this study comparing African American to European American participants ranges from -0 .5

to – 1.1. This study did not have summary data using PCS or MCS. SF-36 does not have a single measure of overall HRQOL.

Summarizing these finding suggest that African American population had a lower mean than the European American population as seen in the negative SMD effect size. While this is insufficient to answer the overall research question definitively, and is open to the charge of comparing different levels of HRQOL, the direction of the data found provides an indication that there was a difference between African American and European American women that that could be considered moderate (d = -0.68 (Figure A10) and d = -0.43(Figure A11).

Analysis

Reports that Met Criteria

During the analysis the failure to find reports that provided statistical comparison of HRQOL between African Americans and European Americans necessitated an examination of the reports that otherwise met the criteria. The original plan for the analysis was to transform the information from the top level of the quality of life instruments into an effect size, compare instruments and then compare the results of the instruments. That was not possible with the lack of comparative data that were available. The reports for the different instruments have been grouped for separate analysis and reporting.

Descriptors of Sample

Of the 22 studies that remained after the coding process, six were dissertations or theses. Table A.5 in Appendix A has details of the dissertations that exited coding.

The remaining 16 reports were retrieved from nine different journals published by six different publishing imprints (see table A.6 for details). The 31 rejected reports that were commercially published were from 21 different journals and 13 different publishers. Publication bias is well known in the area of the publication of significant findings being more likely and impacting meta-analysis (Cooper et al., 2009; Lipsey & Wilson, 2001).

Deviations from the Exclusion Criteria in Accepted Reports

Two reports of the same study were included in the list (Ashing-Giwa et al., 1999; Ashing-Giwa, 1999a). Each contains a component of the necessary information. Some authors chose to publish multiple reports of the same study providing different pieces of information in the reports, and often citing the other work (Lipsey & Wilson, 2001). These two reports were an example where neither contains all the information that would support a meta-analysis. Calculation of SMD effect size was possible in this study.

One study (Ahles et al., 2005) includes 3 male BCS (.7% of study population) and another (Dow et al., 1996) includes a single male BCS (.3% of the study population). Neither of these studies provides separate data for the male participants. Both of these studies used the QOL-CS instrument. Only three studies used that instrument, so the analysis with and without the male breast cancer studies was not possible.

One study (Dhingra, 2002) has a mean time from diagnosis of 4.2 years. It included only statistics for the higher level SF36 (MCS) and (PCS). Two other of the studies only included those higher level components (Carpenter, Ganz, & Bernstein, 2009; Casso et al., 2004).

Race as a Variable in the Coded Reports

Slightly more than half of the studies identified the breakdown of the participant's racial and ethnic background. Twelve studies (13 reports) gave clear breakdown of participants, the overall African American participation in these studies was 8.12% (*n*=472), the European American Participation 87% (*n*=5061), other 4.8% (*n*=280), including two studies that were African American only studies (*n*=124). Table A.7 in Appendix A shows the breakdown of participant numbers in these reports. A further nine studies did not provide a complete or identifiable racial background for participants (*n*= 2527). Table A.8 in Appendix A provides details of these studies.

Measures Used in the Coded Reports

There were six different measures of quality of life used in the studies that exited the coding process. A list of which studies used which instruments can be found in Table A9 in Appendix A.

Only one study allowed the calculation of SMD effect size. However as Lipsey & Wilson (2001, p. 38) point out, while it is not often done, a one variable meta-analysis using central tendency descriptive statistics is both possible and productive. The findings must involve the same variable, operationalized in the same way, so that numerical values have comparable meaning, and that a statistic is used for comparison that allows the determination of the standard error (Lipsey & Wilson, 2001). A separate analysis of the data available from the different instruments was carried out using the arithmetic mean as the effect size. Some studies where the mean was available or could be

calculated but where the standard deviation was not available cannot be included in this analysis.

Further analysis was possible only with the QLI-CVIII, QOL-CS, and MOS SF-36 Instruments using the means of the studies. The three reports (Ashing-Giwa et al., 1999; Ashing-Giwa, 1999a; Casso et al., 2004) that used the CARES-SF also included usage of the SF-36. Two of those reports (Ashing-Giwa et al., 1999; Ashing-Giwa, 1999a) were for the same study and do not report mean and standard deviation. A separate analysis of the Cares-SF was not possible.

The most informative results from the analysis come from the data in the studies that used the SF-36 instrument. Two factors contribute to this, the availability of population norms and the number of studies that were done using the instrument. Additionally the SF-36 subscales allowed for an investigation of differences across the HRQOL spectrum. However, the SF-36 does not provide an overall measure of HRQOL. The (PCS) and (MCS) were the highest level of summary available. Comparison of this instrument with others was impossible in a meta-analysis but allows comparison between studies to be effectively completed.

Description of Analysis Process

All analysis was done using the meta- analysis calculator described by Neyeloff, Fuchs, & Moreira (2012) as an add-on to Excel 2010.

Comparisons between means in the analysis use the effect size as a measure of the difference as the data were meaningful and consistent operationally in each analysis. SMD (Cohen's *d*) is a scale free measure that allows comparison between groups

(Valentine & Cooper, 2003). Interpretation of the effect size was based on the guidance provided by Cohen (1988) of d =0.20 as small, d =0.5 as medium and d =0.8 as large.

Effect sizes for analysis were calculated using an online calculator from the Campbell collaboration (D. B. Wilson, n.d.) and checked with the calculator at University of Colorado, Colorado Springs, (n.d.).

In all cases based on the Q value of the analysis, a random effects model was appropriate as p for the Q statistic in the fixed effect model was significant with $\alpha = .05$. Thus, the true effect sizes of the studies can be concluded to vary. In most of the analysis, I^2 was small i.e. < 20 so that the observed variance in the effect sizes can be considered random (Borenstein et al., 2009).

MOS SF-36

In a study of quality of life measurement, Garratt et al. (2002) found that the SF-36 was the most evaluated HRQOL measure across numerous patient populations. This instrument was used in the largest number of studies in the sample that exited coding (13 studies, 12 reports), most of which reported data on the combined participant sample without racial breakdown. One report (Bloom, Stewart, Oakley-Girvan, Banks, & Shema, 2012) reported on two studies of the same population.

The availability of population norms meant that for the overall population of long-term BCS (including both African American and European American participants as well as those unidentified or identified as other) some indication can be seen in comparison to the US population. In both of the summary scales there was no notable effect size observed, nor were the actual differences in the summary mean indicative of observable

differences in the economic, social or clinical domains of the population. In the SF-36 subscales for the combined population a slightly negative effect size and lower summary means were observed compared to the population norm in the Physical scales. An approximately equivalent summary and individual mean for the General Health and Vitality scales was observed, as were means generally higher than the population norm for Social, Emotional Role and Mental Health scales. None of the outcomes would be expected to be observable in the economic, social or clinical dimensions.

Insufficient data meant that it was not possible to draw a conclusion as to the impact of race on the scoring across the subscales with only one study (Chen, 2005) having data sufficient to calculate the SMD effect sizes on the summary scales. This study suggests African American participants overall had a lower HRQOL than European American participants.

SF-36 Instrument

The instrument has been used in both healthy and clinical populations and in cross sectional and longitudinal studies (Zebrack, 2004). It is a standardized, general measure of health status with normative data available and has been used in oncology populations including breast cancer (Zebrack, 2004). The SF-36 has a 0.78 or greater test retest validity and an internal consistency that varies between 0.78 and 0.93. It is sensitive to changes in function over time and can distinguish differences in clinical status, age and race (Zebrack, 2004).

The questionnaire measures quality of life across eight health domains that are both physically and emotionally based. The domains are physical functioning (PF) role

limitations due to physical health (RP), bodily pain (BP), general health (GH), Vitality (VT), Social Functioning (SF), role limitations due to emotional functioning (RE), and mental health or emotional well-being (MH). A single item identifies perceived changes in health (Ware, 2003). A 5 point difference is considered clinically meaningful in the domain scores (Ware et al., 1993).

Two summary scores are generated from these eight domains the Physical Component Summary (PCS) and the Mental Component Summary (MCS) that account for more than 80% of the variance in the subscales (Ware & Kosinski, 2001). The PCS and MCS were developed using norm based scoring with a mean of 50 and a standard deviation of 10 (Ware & Kosinski, 2001).

While several studies have been done to assess the Minimal Clinically Important Differences (MCID) to be able to interpret the SF-36 subscale scores for a clinical population (Keurentjes, Tol, Fiocco, Schoones, & Nelissen, 2012; Wyrwich et al., 2004; Wyrwich, Tierney, Babu, Kroenke, & Wolinsky, 2005), the consensus appears that the MCID is relatively illness specific. So for example asthma and chronic obstructive pulmonary disease (COPD) have similar MCID (Wyrwich et al., 2005) for the SF-36, MCID for cardiac issues (Wyrwich et al., 2004) or hip replacement surgery (Keurentjes et al., 2012) were quite different. MCID where available were only related to sub scores of the SF-36 and no reference could be identified for BCS, or for the summary scales of the SF-36.

A report on the effect size in SF-36 usage in studies (Lincoln, 2000) looked at change in percentile rank of the quality of life of the study population in comparison to

the population norms for the US. Lincoln (2000) used only what were considered high quality studies, where methodology included randomization and control groups. A change in the PCS or MCS scores of 5 points or an effect size of 0.5 would have social, clinical and economic implications (Lincoln, 2000). No breast cancer or general cancer studies were included in this report. While a change of 5 points in the mean for the SF-36 cannot be considered conclusive, I used it as a benchmark that would indicate more attention should be paid to the results.

Demographic Information from the Studies that Used SF-36

Table 13

Racial Identification of Participants in Studies Including the SF-36

Title	Initial Author	Date Pub.	total subjects	African American subjects	European American subjects	Other subjects
Quality of life of younger breast cancer survivors: persistence of problems and sense of well-being.	Bloom	2012	312	18	227	67
Complementary and alternative therapies among very long-term breast cancer survivors	Carpenter	2009	371		335	36
Quality of life of 5-10 year breast cancer survivors diagnosed between age 40 and 49.	Casso	2004	216		200	16

Title	Initial Author	Date Pub.	total subjects	African American subjects	European American subjects	Other subjects
Long-term quality of life assessment in post-menopausal women with primary breast cancer	Chen	2005	2115	92	1972	51
Functional Impairment and the Economic Consequences of Female Breast Cancer	Chirikos	2002	105			
Health-related quality of life, age, and comorbidity in breast cancer survivors 1 to 12 years post-treatment.	Dhingra	2002	257			
Breast cancer in younger women: reproductive and late health effects of treatment.	Ganz	2003	577	67	405	105
Surviving cancer: A comparison of 5-year disease-free breast cancer survivors with healthy women.	Helgeson	2005	267		251	16
Associations between lifestyle factors and quality of life among older long-term breast, prostate, and colorectal cancer survivors.	Mosher	2009	321			
Social capital, social support, and quality of life among long-term breast cancer survivors.	Petersen, D.	2008	387		284	103

Title	Initial Author	Date Pub.	total subjects	African American subjects	European American subjects	Other subjects
Relationship of Optimism-Pessimism and Health-Related Quality of Life in Breast Cancer Survivors.	Petersen, L.R.	2008	255			
Long-term survivorship in breast cancer: Quality of life at five years and beyond	Trimble	1997	226	21	205	
	Total participants		5409	198	3879	343
	Identified by race		4430	4.5%	87.8%	7.8%

Twelve studies passed through the coding that used the SF-36 instrument as the measure of HRQOL. In these studies, 989 participants or 18.3% were not identified by racial or ethnic background. The studies included 198 African American participants or 4.5% of the participants in this group, and 343 or 7.8% were non-African American and non-European American. The remaining participants were 3879 or 87.8% were identified as European American.

Physical Component Summary Score Analysis

PCS SF-36

Study	Sample Size	Mean (95% CI)
Bloom (10) 2012	312	49.24 (48.13-50.35)
Bloom (5) 2012	312	50.78 (49.79-51.77)
Casso 2004	216	48.89 (47.49-50.29)
Chirikos 2002	105	49.9 (47.99-51.81)
Dhingra 2002	257	48.81 (47.5-50.12)
Ganz 2003	577	50.2 (49.42-50.98)
Mosher 2009	321	44.8 (43.8-45.8)
Petersen, D. 2008	387	49.17 (48.2-50.14)
Petersen, L.R. 2008	255	39.72 (38.23-41.21)
Trimble ALL 1997	172	46.2 (44.53-47.87)
Summary		**47.78 (45.9-49.67)**
Boehmer 2012	438	37.82 (36.49-39.15)
Carpenter 2009	371	52.67
Chen AA 2005	105	46.30
Chen EA 2005	3224	50.10
Helgeson 2005	267	53.60
Trimble AA 1997	21	45.6 (41.02-50.18)
Trimble EA 1997	205	45.8 (44.2-47.4)

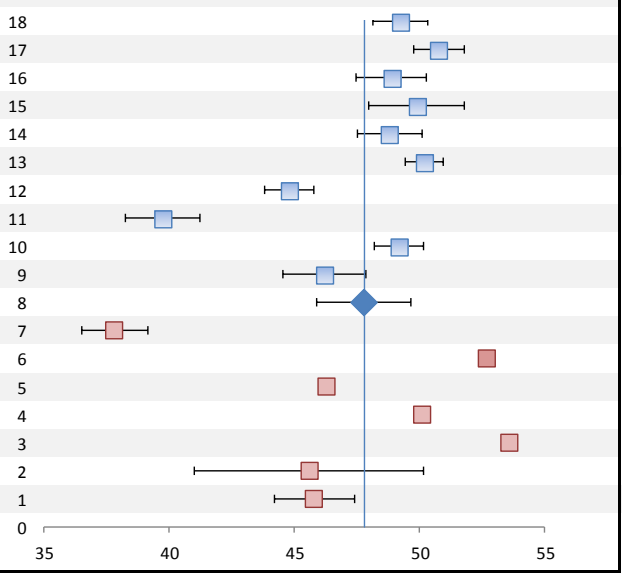

Figure 9. Forest plot of PCS scores on studies that use the MOS 36 (all versions).
Note: Studies in red were not included in the analysis but are plotted to indicate how they relate to the studies that are included

PCS has a mean of 50 and a standard deviation of 10. US population norms for PCS; M=49.12 SD 10.45 were available from 1998 for female only populations (SF-36.org, n.d.). An effect size of d = -0.039 did not reach the criteria of small in comparing this population to the general female norm. As this difference equates to less than 2 points difference in the mean there would be no indication that this difference would be socially, economically or clinically obvious.

Several studies using the SF-36 could not be included in the analysis but were included in the plot for comparison purposes. One study reported PCS and MCS but only reported means without standard deviations or other statistics that could be used to calculate confidence intervals (Carpenter et al., 2009). Two studies reported full statistics

for the eight domains but did not report PCS and MCS (Chen, 2005; Helgeson & Tomich, 2005). While those can be calculated using the PCS/MCS (Quality Metric, n.d.) confidence intervals cannot be calculated for these statistics. One study (Trimble, 1997), reported the African American and European American participants separately. These studies were reported on the forest plots that follow with a single point rather than with the confidence intervals, with the associated marker on the chart in red.

The lowest score of the studies included in the meta- analysis (Petersen et al., 2008) has an effect size difference from the summary of all included studies of d = -0.16 which falls short of the threshold for a small effect.

Seven of the studies had means above the summary mean. The effect size from the lowest (Petersen et al., 2008) to the highest (Bloom et al., 2012) study was d= -0.998 was large. The two studies had some different characteristics that may explain this difference. The lowest mean of the group (L. R. Petersen et al., 2008) drew from a population who had completed the Minnesota Multiphasic Personality Inventory (MMPI) "to address diagnostic or management dilemmas faced by physicians because of the suspected intermingling of physiologic and psychological factors" (L. R. Petersen et al., 2008, p. 19). Without further information, it was not possible to draw conclusions as to the impact of the difference in participants, but it should be noted that there may be other factors that impacted the low outlier. The highest scoring cohort (Bloom et al., 2012) were tested 5 years later, and an effect size d = -0.099 showed a slight increase in PCS across the cohort amounting to less than two points of difference and therefore unlikely to be clinically, socially or economically impactful.

Of the studies that were not included in the meta-analysis but added for comparison purposes, three had means lower than the summary mean, all less than two points lower than the summary mean. Both of the small African American samples were lower than the summary mean. Both samples from one of the dissertations included for comparison (Trimble, 1997), were lower than the sample mean. While the large European American sample (Chen, 2005) was more than 3 points above the sample mean, with a difference of more than 3.8 points between the African American and European American samples.

While population norms were available, not all of the studies used the same population normative standards. Seven of the studies (Bloom et al., 2012; Ganz, Greendale, Petersen, Kahn, & Bower, 2003; Mosher et al., 2009; D. Petersen, 2008; L. R. Petersen et al., 2008; Trimble, 1997) used the 1990 norms. In three studies (Casso et al., 2004; Chirikos, Russell-Jacobs, & Jacobsen, 2002; Dhingra, 2002) the norm used could not be determined.

As this is norm based scoring a second analysis was run on only the studies normed using 1990 data. The following figure 10 presents that analysis. No comparison studies were included as it could not be determined which norms were used.

PCS SF-36 1990 normed data only

Study	Sample Size	Mean (95% CI)
Bloom (10) 2012	312	49.24(48.13-50.35)
Bloom (5) 2012	312	50.78(49.79-51.77)
Ganz 2003	577	50.2(49.42-50.98)
Mosher 2009	321	44.8(43.8-45.8)
Petersen, D. 2008	387	49.17(48.2-50.14)
Petersen, L.R. 2008	255	39.72(38.23-41.21)
Trimble ALL 1997	172	46.2(44.53-47.87)
Summary		**47.2(43.67-49.72)**

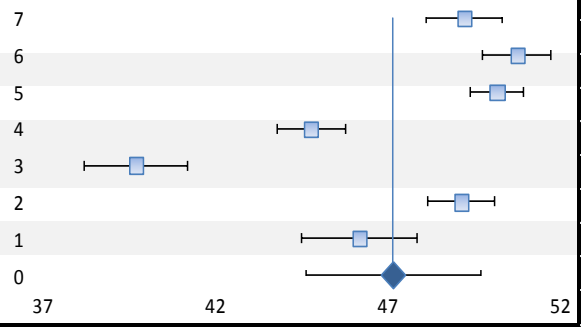

Figure 10. 1990 normed studies in for PCS.

The summary mean of this analysis was slightly lower than the full analysis above. Compared to the population mean of 50 (female only norms for 1990 were not found, SF-36.org, n.d.), the SMD effect size of $d = 0.064$ and 2.8 points difference in the mean would not be expected to have measurable social, economic or clinical impact. Removing the studies that were normed to other standards did not change the overall conclusion that the difference between summary mean and the population mean norm would not be sufficient to suggest that there would be social, clinical or economic impact.

The PCS data for the overall population of studies, the SMD effect size between the summary mean and the population norm is less than the cutoff point to be considered a small effect. The difference between studies was large and suggests that the use of the random effects model in the analysis was appropriate.

Mental Component Summary Score Analysis

MCS SF-36

Study	Sample Size	Mean (95% CI)
Bloom (10) 2012	312	51.96(50.85-53.07)
Bloom (5) 2012	312	51.09(50.1-52.08)
Casso 2004	216	46.62(45.22-48.02)
Chirikos 2002	105	50.7(48.79-52.61)
Dhingra 2002	257	47.58(46.27-48.89)
Ganz 2003	577	49.4(48.62-50.18)
Mosher 2009	321	56.4(55.4-57.4)
Petersen, D. 2008	387	52.44(51.47-53.41)
Petersen, L.R. 2008	255	50.75(49.26-52.24)
Trimble ALL 1997	172	51.7(50.03-53.37)
Summary		**50.88(49.27-51.93)**
Boehmer 2012	438	50.6(49.66-51.54)
Carpenter 2009	371	49.79
Chen AA 2005	105	53
Chen EA 2005	3224	54.5
Helgeson 2005	267	52.8
Trimble AA 1997	21	51.4(46.82-55.98)
Trimble EA 1997	205	54.6(53-56.2)

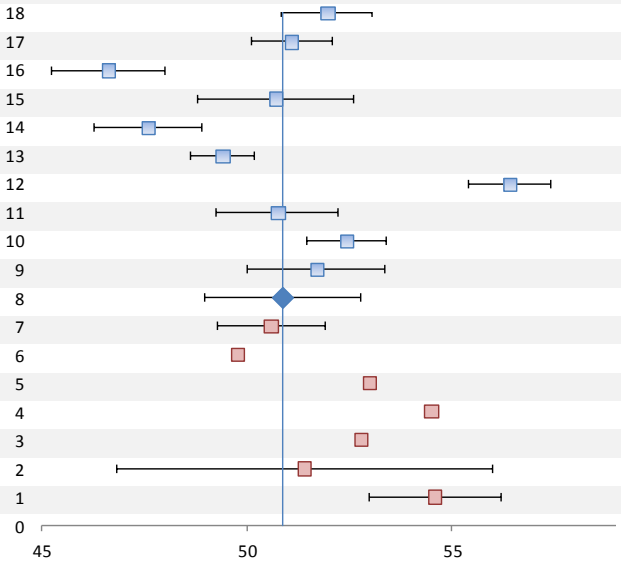

Figure 11. Forest plot of MCS scores on studies that use the MOS 36 (all versions).
Note: Studies in red were not included in the analysis but are plotted to indicate how they relate to the studies that are included

MCS has a mean of 50 and a standard deviation of 10 for the total US population in 1998. Using US population norms for MCS female only populations (1998) (SF-36.org n.d.) MCS has a mean of 50 and a Standard deviation of 10 for the total US population in 1998. Norm for MCS was 48.96 SD 10.67. An effect size of $d = 0.055$ suggests that there was a slightly higher assessment from the long-term breast cancer population that from the female population in general but that this effect would not even be considered as small. As this difference equates to a 1.92 point difference in the means, there would be no indication that this difference would be socially, economically or clinically obvious.

The effect size from the lowest (Casso et al., 2004) to the highest (Mosher et al., 2009) study was $d = 1.16$ was large. This effect size translates to a 9.78 point difference in the means of the two studies and would suggest an overall difference that should be perceptible on a social, economic or clinical level.

Five of the ten included studies had means lower than the summary mean. All but two of the studies had means higher than the normed sample. Of the studies that were not included in the meta-analysis but added for comparison purposes, only one had a mean lower than the summary mean. Both African American samples (Chen, 2005; Trimble, 1997) were higher than the summary mean, but the difference was less than 3 points. Both of the European American samples (Chen, 2005; Trimble, 1997) were more than 3.5 points above the sample mean. In both studies, the African American samples had a lower MCS than the European American samples, although the difference would not likely have been noticeable, in a social, economic or clinical perspective.

MCS SF-36 1990 normed data only

Study	Sample Size	Mean (95% CI)
Bloom (10) 2012	312	51.96(50.85-53.07)
Bloom (5) 2012	312	51.09(50.1-52.08)
Ganz 2003	577	49.4(48.62-50.18)
Mosher 2009	321	56.4(55.4-57.4)
Petersen, L.R. 2008	255	50.75(49.26-52.24)
Petersen,D. 2008	387	52.44(51.47-53.41)
Trimble ALL 1997	172	51.7(50.02-53.37)
Summary		**51.97(50.31-54.77)**

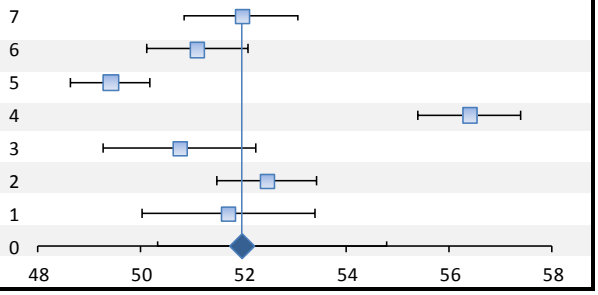

Figure 12. MCS study data for 1990 normed studies only.

As with the PCS a separate analysis was done with only those studies normed for the 1990 US population data (SF-36.org, n.d.). The previous Figure (12) is a forest plot of that analysis. The summary mean of this analysis was slightly higher than the full analysis above. However compared to the population mean of 50 (female only norms for 1990 were not found, SF-36.org, n.d.), the SMD effect size of $d = 0.0595$ was less than a two point difference with no observable effect in the population expected from that difference. Removing the studies that were normed to other standards did not change the overall conclusion that while there was a small difference between summary mean and the population mean norm, the difference would not be sufficient to suggest that there would be social, clinical or economic impact that could be measured.

There was a 7 point difference between the lowest mean and the highest in the studies. They were the only studies that fall outside the confidence interval of the summary mean and would be considered outliers. There was not enough information available in the studies to do a moderator analysis so that it was difficult to assess if this can be attributed to study characteristics or to population characteristics. A 7 point difference in quality of life would suggest differences that were observable. All others studies would not be expected to have observable impacts.

The MCS data for the overall population of studies, the SMD effect size between the summary mean and the population norm was less than the cutoff point to be considered a small effect. The difference between studies was large and suggests that the use of the random effects model in the analysis was appropriate.

Use of the Random Effects Model in the Analysis of the Component Scales

Q was significant in the fixed effects model at $p = 0.05$ for all these analyses causing a rejection the null hypothesis of homogeneity and confirming that the variability across studies was more than would be expected from sampling error alone. The choice of the Random Effects model was appropriate for both of these distributions of effects. I^2 was negative in all analysis and therefore was set to 0 for the random effects model suggesting no inconsistency in the Random Effects model.

MOS SF-36 Subscales

Nine studies had data that enabled the analysis of the summary mean for the subscales of the SF-36. The following studies were included in the subscale analysis.

Table 14

Studies Included in the SF-36 Subscale Analysis

Study Title	First author	Date Pub.
Quality of life of younger breast cancer survivors: persistence of problems and sense of well-being.	Bloom	2012
Long-term quality of life assessment in post-menopausal women with primary breast cancer	Chen	2005
Functional Impairment and the Economic Consequences of Female Breast Cancer	Chirikos	2008
Breast cancer in younger women: reproductive and late health effects of treatment.	Ganz	2003
Surviving cancer: A comparison of 5-year disease-free breast cancer survivors with healthy women.	Helgeson	2005
Associations between lifestyle factors and quality of life among older long-term breast, prostate, and colorectal cancer survivors.	Mosher	2009
Social capital, social support, and quality of life among long-term breast cancer survivors.	Petersen, D.	2008
Relationship of Optimism-Pessimism and Health-Related Quality of Life in Breast Cancer Survivors.	Petersen, L.R.	2008
Long-term survivorship in breast cancer: Quality of life at five years and beyond	Trimble	1997

The following chart compares the means for the subscales in the meta- analysis of the studies with that of the population norms. These population norms are for the total

US population for 1990(Quality Metric, n.d.), the SMD effect sizes were calculated using the online calculator available from the Campbell Collaboration website (D. B. Wilson, n.d.). The differences were summarized in Fig 13 that follows.

In the chart, the effect size follows the subscale name and the absolute difference in mean between the subscale summary score and the population mean is in brackets following that. No SMD effect size reaches the criteria for small. From this analysis the subscale means would not be expected to have any discernable social, economic, or clinical difference for long-term BCS from the general population. Detailed data on the subscale analysis is provided in Appendix A.

Two absolute mean differences in the (PF) and (PR) scales were just over the 5 point threshold of what might be observable. The trend that in the Physical subscales the study population scores slightly lower and the Mental subscales the study population scores slightly higher can be observed, but the differences were small.

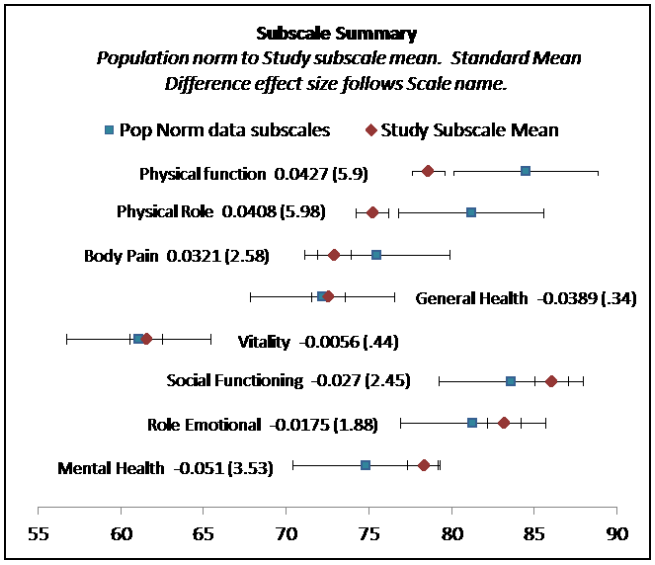

Figure 13. Summary analysis subscale means and 95% CI intervals compared to population norms for studies that used SF-36. Norm =1990 US general population.

Overall Observations of the SF-36 Data

As the analysis done on the studies used a meaningful statistic, the dispersion of studies around the summary mean and in comparison to the population norms provided insight into how wide the differences were in the studies. One study (L. R. Petersen et al., 2008) consistently reported the lowest means on the subscales except for the Physical Functioning (PF) and Physical Role (RP) subscales. This study did not appear to be an outlier in the MCS analysis but did report the lowest study mean on the PCS. This difference reflects that the PCS was not just developed from the two physical scales but also includes input from other scales (Ware & Kosinski, 2001). The summary scales do not always give a clear indication of the source of variation using this instrument.

As there was not always a clear relationship between results on subscales and results on the summary scales the subscale scores can be informative. The European American population in Chen's (2005) study consistently has either the highest or second highest mean across six of the eight subscales (RP, BP, V, SF, RE, MH) but did not stand out in the analysis of either the MCS and PCS. Conversely Mosher et al. (2009) shows up as a high outlier in three subscales (SF, RE, MH) and both of the MCS analysis.

There was however a consistency with a slightly lower analysis mean compared to the female population norm for PCS, and lower PF, PR, and BP assessments from the long-term BCS. Likewise, an indication of better than the norm status on the MCS was consistent with the analysis means for the V, SF, RE, and MH subscales where the study means were equivalent or higher than the population norm.

While the summary of the studies included did not show a difference from the population norms. Individual studies do show differences where the difference in the mean was greater than what might be expected to be observable in clinical, economic or social observations.

QOL-CS Studies

The QOL-CS Instrument

This instrument is modeled after work done at the City of Hope National medical Center (Dow et al., 1996). The QOL-CS is a 41 item self-report instrument that assesses the physical, psychological, social and spiritual domains of quality of life using an 11 point scale with 0 being the worst possible outcome and 10 the best possible (Ahles et al., 2005). Test related reliability for the overall tool is reported between $r = 0.81$ and 0.90 (Zebrack, 2004, p. 247) and retest reliability for each scale is reported as Physical ($r = 0.88$), Psychological ($r = 0.88$), Social ($r = 0.81$), and spiritual ($r = .90$) (Dow et al., 1996). Cronbach's alpha for the entire QOL-CS was reported between $r = 0.71$ and 0.93 (Zebrack, 2004, p. 247) and internal consistency for the subscales were Physical (r=0.77) Psychological (r= 0.89), Social ($r = 0.81$), and Spiritual (r= 0.71) (Dow et al., 1996, p. 266). These indicate satisfactory reliability (Cimprich et al., 2002, p. 87).

Survivor scores were observed to be higher than those with active disease (Zebrack, 2004, p. 247). The instrument was designed specifically to measure quality of life in cancer survivors and covers psychosocial issues that are relevant to survivorship. While it is useful in identifying survivor issues it does not currently support longitudinal

changes across the cancer trajectory starting with active treatment phases, nor does it allow comparison to normal populations (Zebrack, 2004).

Table 15

Studies Using QOL-CS

Title	Initial Author	Date Pub.	total subjects	*African American* subjects	*European American* subjects	Other subjects
Quality of life of long-term survivors of breast cancer and lymphoma treated with standard-dose chemotherapy or local therapy.	Ahles	2005	549			21 men
Age at Diagnosis and Quality of Life in Breast Cancer Survivors.	Cimprich	2002	105	9	96	0
An evaluation of the quality of life among long-term survivors of breast cancer.	Dow	1996	294		93	7 other 1 male

Demographics in the QOL-CS studies. None of the studies that used the QOL-CS (Table 15) to measure HRQOL reported results for racial categories separately, and they were not consistent in how they reported racial and ethnic differences. Cimprich et al., (2002) reported 96 white and nine non-white. The other two studies (Ahles et al., 2005; Dow et al., 1996) do not provide a breakdown of African American participants.

There were 22 male breast cancer patients included in the samples for two of the studies. The Ahles study (Ahles et al., 2005) included 50 patients or less than 10% who were greater than stage 2. The overall mean time since diagnosis was 10.3 years plus or minus 5.3 years. So it was possible that some participants were less than5 years since diagnosis but that was not identified. The Ahles study (Ahles et al., 2005) mean and SD were calculated from the different group data presented. As this study also included Lymphedema patients and a comparison between patients treated with chemotherapy and those treated only with local interventions, and or tamoxifen, long-term breast cancer groups were combined to calculate the overall data for the study. The Dow study (Dow et al., 1996) compared patients who had survived greater than 5 years and less than 5 years. This study includes data from the long-term survivors. Dow et al., (1996) also used the FACT- G as an instrument in the study. This analysis did not find sufficient studies to do a separate analysis on the FACT- G. A qualitative comparison provided that the FACT- G was consistent with the QOL-CS and that Physical subscales were more likely to be scored higher than the Psychological subscale, and that the social and spiritual subscales fell between them. While interesting, this comparison added little to the analysis. Dow et al., (1996) found that time since diagnosis improves overall quality of life in the population studied. Cimprich et al., (2002) focused on the differences in age at diagnosis and found that it was a significant predictor of quality of life, but also that longer survival times indicated improved quality of life.

QOL-CS studies

Study	Sample Size	Mean (95% CI)
Ahles, 2005	172	7.29(7.21-7.37)
Cimprich, 2002	577	7.34(7.32-7.36)
Dow, 1996	321	6.51(6.36-6.66)
Summary		**7.06(3.69-10.43)**

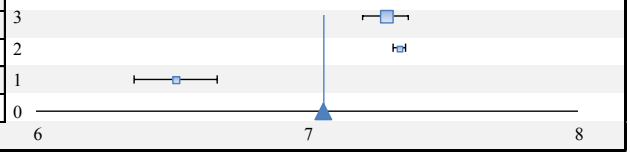

Figure 14. Analysis of studies using QOL- CS as study instrument.

Analysis of studies that used the QOL-CS. The small number of studies that used this measure, and the lack of population norms make interpretation of the data problematic. It was difficult to put the studies into context. It can be noted that the summary mean was above the midpoint of the instrument.

QLI-CVIII Studies

The QLI-CVIII instrument.

The QLI-CVIII was developed based on a model of HRQOL that takes into account both the assessment of an item and its relevance to the life of the person responding (Ferrans et al., 2005). Quality of life scores have been shown to differentiate between different symptom level in areas of pain, depression and coping with stress (Lee, 1997). The Cronbach's alpha of 0.95 for the total instrument suggesting high consistency within the instrument (Lee, 1997) with BCS (Leak et al., 2008) and a range from α = 0.85-0.98 across studies (Keating, 2007). The instrument has four domains confirmed by factor analysis and representing 91% of the variance (Keating, 2007) Health and functioning, psychological/ spiritual, social and economic, and family (Leak et al., 2008). It is scored in a likert type scale where 1 = very dissatisfied to 6 = very satisfied (Leak et

al., 2008). Higher scores represent better quality of life (Keating, 2007). One higher order factor representing overall quality of life was identified (Keating, 2007).

Table 16

Studies Using the QLI-CVII Instrument

Title	Initial Author	Date Pub.	total subjects	African American subjects	*European American* subjects	Other subjects
Social support, God locus of health control, and quality of life among African American breast cancer survivors	Huff	2012	94	94	0	0
Describing psychosocial risk factors in breast cancer diagnosis and survivorship	Keating	2007	102	0	102	
Symptom distress, spirituality, and quality of life in African American breast cancer survivors.	Leak	2008	30	30		
Quality of life and breast cancer survivors. Psychosocial and treatment issues.	Lee	1997	100	3	88	9
Totals			326	127	190	9

Demographics of the studies using the QLI-CVIII. Two of the studies that used the QLI-CVIII were totally African American in participation. One was only European American and one had 3% of the participants identified as African American.

Huff (2013) did not identify the staging of the cancer diagnosis of the population used. The mean time since diagnosis was 82.80 months which met the acceptance criteria, but only 46.7% of the population was greater than 60 months into their cancer trajectory. Huff (2013) found that social support was a predictor of quality of life and that those who lived in the suburbs had a higher quality of life than those who lived in either city or rural settings. This study was totally based on an African American Population as was the study that investigated how demographic characteristics, symptom distress and spirituality related to quality of life (Leak et al., 2008). It found a statistically significant relationship between spirituality and higher quality of life ($p<.05$) and an inverse correlation between higher severe symptom distress and quality of life ($p<.05$). The mean time since diagnosis was 5.6 years, and no significant relationships were found of demographic characteristics and quality of life in this population. The samples size of this study was small, and there was no analysis of the impact of years since diagnosis on quality of life.

A relationship between time since diagnosis and quality of life was found in a study focused on how social support impacted quality of life (Lee, 1997). This study was primarily 88% European American with a mean time since surgery of 14 years, with more than 40% of the participants having a time since surgery of greater than 13 years. In a study of psychological risks in breast cancer survival Keating, (2007) using a

European American only population found a moderate to good quality of life in a relatively small sample. This study found a significant negative correlation with depression.

QLI-CVIII studies

Study	Sample Size	Mean (95% CI)
Huff,2012	94	21.5(20.49-22.51)
Keating ,2007	102	23.86(22.93-24.79)
Leak,2008	30	26.6(25.56-27.64)
Lee,1997	100	30.71(29.86-31.56)
Summary	**226**	**25.67(22.3-29.04)**

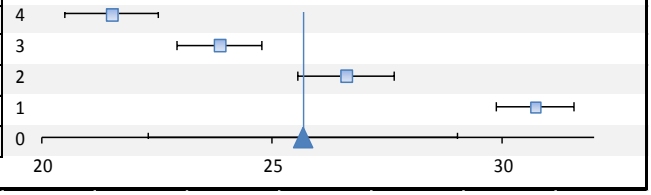

Figure 15. Analysis of studies using QLI-CVIII as study instrument.

Analysis of the QLI-CVIII data. Two studies primarily of African American participants and two of European American participants, using the same operational definition of the concept allowed for comparison by deriving summary means from the two like studies. These were then a SMD based on dissimilar *n* was calculated.

The grand mean of *n* = 124 African American participants (Huff, 2013; Leak et al., 2008) M=0 22.75 SD=0 5.07 and for the *n* = 202 primarily European American participants (Keating, 2007; Lee, 1997) was M =0 27.25 SD =5.68. Giving a SMD of *d* = 0.8247 with 95% Confidence Interval (CI) of -1.0571 to -0.5923 *v* = 0.0141. This effect size would be considered large and would be expected to be observable in any of the social, economic or clinical contexts. The sample size of this comparison was small and alone would not be particularly useful as an overview of the impact.

Conclusion

The results of the analysis of the 22 studies in the final study population suggest that overall long-term survivors of early-stage breast cancer when all racial backgrounds

were included do not differ from the general population in a way sufficient to assume there would be any noticeable difference in their assessment of their HRQOL in social, clinical or economic dimensions.

For the small sample of data where African American and European American women could be compared, a difference in effect size that ranged from medium to large suggest that African American women may have assessed their survival at a lower level than European American women. That this outcome may be subsumed in most reports because of the lower participation of African American women in studies, or the failure to report data separately for races as the difference did not reach significance in a particular study. In the small number of studies where data could be compared, the percentage of African American participants was higher than the overall study population and higher than the percentage of African American women reported in the overall breast cancer survival population (Susan G. Komen Circle of Promise, 2009).

Data available was insufficient to assess if different instruments had an effect on the outcome. Only one instrument had sufficient data to examine the components for the overall sample including all races, which showed no appreciable difference from the population norms. Only one study had data to allow the calculation of the effect size for the difference between African American and European American women, so analysis was not able to be conducted at the subscale level. The small number of studies in both the QOL-CS and QLI-CVIII study populations as well as the lack of population norms available meant that few conclusions could be drawn about the usefulness of those instruments in this study.

Chapter 5: Discussion, Conclusions, and Recommendations

Overview

Why the Study Was Done

A large and growing number of women survive early-stage breast cancer for more than 5 years (American Cancer Society, 2011). About 12% of those women were of African American racial designation (Susan G. Komen Circle of Promise, 2009). Long-term breast cancer survival may have additional impacts than those noted in short-term survival. Some of these differences can be captured using HRQOL as the outcome measure (Lipscomb, Gotay, & Snyder, 2004b).

The impacts of long-term survival may be different because of racial identification or because it is a proxy for other cultural or socioeconomic factors that lead to a different experience of chronic illnesses such as breast cancer (Vin-Raviv et al., 2013). In addition, there may be disparities in the treatment of patients of different racial identification that show up in long-term impacts (Bradley et al., 2001; Dignam, 2000; Li & Malone, 2003).

The review of the literature presented in Chapter 2 provided contradictory evidence of a difference between African American and European American long-term BCS, especially when the domains of HRQOL were examined. An understanding of if there was a difference, how big it was, and where it was most visible would allow more effective research into the problem and provide direction for changing the way that women of different races were treated after a breast cancer diagnosis.

How the Study Was Done

A meta-analytic approach was chosen to allow the extensive literature on breast cancer survival to be identified and selected for analysis to determine if there were data available to determine if there was a difference between African American and European American long-term BCS (Chalmers, 2007; Cooper et al., 2009).

Electronic searches of databases returned 59 reports, dissertations, and articles that met the predetermined criteria and that were entered into the coding phase of meta-analysis. Of those 59 documents, 22 studies were identified that could theoretically match predetermined criteria. A meta-analysis requires that at least two studies would be available for comparison (Lipsey & Wilson, 2001). Unfortunately, during the search it was identified that only one study, reported in two different reports, (Ashing-Giwa et al., 1999; Ashing-Giwa, 1999a) provided the data for comparison of African American and European American BCS on the dependent variable of this study, HRQOL. While SMD was the effect size that was planned to be used for this study, there were no data to calculate it as a comparison between African American and European American women for most studies. While it is not often done, it was possible to do a meta-analysis on the mean of studies (Lipsey & Wilson, 2001) and consequently, the studies were coded to identify where possible comparisons for the total population of BCS could be compared across HRQOL instruments.

Studies that fell into groups that used the same instrument were compared using meta-analytic techniques. By using the mean as the effect size statistic for those

techniques, it was possible to find summary data that were both meaningful and usable when I could compare them to population norms.

The Questions Asked

The primary question pertained to the difference, if any, between the way African American and European American long-term BCS perceive their survival as measured by HRQOL. In addition, there were several questions related to testing moderating variables, socioeconomic factors, age, or the instrument used. I hoped that the various domains of HRQOL including at least physical, mental, social, and perhaps spiritual, could be differentiated and could be seen to impact the perception of long-term survival.

The Findings

Only one study reported in two different reports, provided data at the level of overall HRQOL that allowed a SMD to be calculated between African American and European American participants (Ashing-Giwa et al., 1999; Ashing-Giwa, 1999a). African Americans, when compared to European Americans, showed a negative SMD effect size that fell in the moderate to large range. There were not enough data to calculate the effect size for multiple studies.

An analysis of HRQOL as operationalized in MOS SF-36 was conducted on 13 studies that used that instrument. The SF-36 is a standardized, general measure of health status with normative data available from the United States population, but not for different racial backgrounds, and it has been used in oncology populations including breast cancer (Zebrack, 2004). SMD no greater than $d = 0.07$ (i.e. no greater probability than chance) were found between the total population of long-term breast cancer patients

(including both African American and European American participants) and SF-36 population norms (1990). These findings were for the summary scales of the SF-36, (PCS and MCS) and the subscales that report on the separate dimensions of HRQOL.

It was not possible to draw conclusion as to the impact of race on the scoring across the subscales. Only one study (Chen, 2005) reported subscale data using the SF-36 for African American (n = 101) and European American women (n = 3,150) separately. This dissertation was a study of women 5 years post breast cancer from registry data; it included both Canadian and U.S. participants, but only the U.S. data were analyzed for my study in keeping with the criteria set for inclusion. African American women scored lower on all subscales with an effect size in the low to moderate range.

The small number of studies that used either the QOL-CS or the QLI-CVIII instruments did not allow further analysis of the studies that used those instruments. Lack of population norms available for those instruments meant that no further interpretation was possible.

The percentage of African American participants was lower in the 22 studies in the analysis phase than in the BCS population in general. Nine studies did not report racial breakup of participants and few reported the data for African American and European American populations separately.

The Interpretation of Findings

The primary interest of this research was to understand if there was a difference between African American women and European American women in how they perceived survival from breast cancer. The criterion for inclusion was that the women

had to have been diagnosed with early-stage breast cancer and be at least 5 years post diagnosis. The outcome measure was operationalized to be a standard measure of HRQOL.

Forty studies were found where the population was consistent with the criteria and of these, only one allowed for the calculation of SMD between the HRQOL measure for African American and European American BCS (Ashing-Giwa et al., 1999; Ashing-Giwa, 1999a). Other studies allowed for the calculation of the effect size for a component of the SF-36 instrument. These studies were at either the summary level of the PCS and the MCS, the two summary scales of the SF-36 (Trimble, 1997) or at the subscale level for the eight different subscales that make up the SF36 (Chen, 2005). An effect size using four studies that used the QLI-CV III was calculated. Two of the studies had n = 124 African American only participants (Huff, 2013; Leak et al., 2008) and two had n = 202 primarily European American participants (Keating, 2007; Lee, 1997). The SMD statistic produced a large effect size (Cohen, 1988) and would be expected to be observable in any of the social, economic or clinical contexts.

The outcome of this study was that there was no possibility of conducting a valid meta-analysis. Studies where the statistic could be calculated gave a medium to large effect size suggesting that there would have been an observably lower quality of life for long-term African American BCS that for their European American counterparts.

As an alternative analysis approach and to attempt to see if the data found would suggest other avenues of research, an analysis using meta-analytic techniques was done using the mean and standard deviation statistics that were provided for the overall

population samples in 22 studies. These studies did not provide data to analyze racial differences. A comparison of long-term breast cancer patients of all races with the overall population norms would indicate if the research showed lower HRQOL across the BCS population or if only the case in the small number of studies that showed a difference in the African American population.

Only one instrument had population norms for a racially integrated population. The SF- 36 was the most used instrument in the studies found (13 studies) and provided population norms against which to compare the summary findings. Other instrument groupings could not be compared in this way. The findings for the SF-36, total participant population suggested that there would be no observable difference between the long-term breast cancer participants and the general US population in HRQOL in the clinical, economic or social dimensions.

The review of the literature before the meta-analysis was attempted suggested that there would be differences between the populations and that at least on some HRQOL dimensions there would be effect size differences that were observable (Giedzinska et al., 2004; Paskett et al., 2008). Differences seen in the literature between African American and European American BCS included their coping strategies, treatment methods, and life impact (Ashing-Giwa, Padilla, Tejero, Kraemer, et al., 2004). Other differences including physical functioning (Bowen et al., 2007; Deimling et al., 2003; Paskett et al., 2008), emotional functioning (Ashing-Giwa et al., 2007; Bowen et al., 2007; Giedzinska et al., 2004) and social functioning (Bourjolly et al., 1999) were observed.

During the coding phase reports that used nonstandard instruments or where only one study used an instrument were excluded if a SMD could not be calculated. Two reports of the same study (Mishel et al., 2005; Porter et al., 2006) that had interesting information as to the survival of African American and European American women and the differences observed, used a quality of life measure that was focused on mood states as their primary measure. They were the only studies that used that measure so even at the lowest level comparison of grouping studies by instrument there was no statistical comparison that I could make. In these studies approximately 29% of participants were African American (n = 149 from a study total of n = 509 participants). The studies used the data from an intervention to support develop a causality model for negative mood states. Data were not provided in either report of the different scores for African American and European American women and the only comment was "There was no significant change on the total POMS or any of the subscales" (Mishel et al., 2005, p. 973).

While most of the findings of these two studies suggest that there were similarities between African American and European American long-term survivors. The analysis of the antecedents for negative mood state suggests that there were differences especially related to physical health problems. The authors suggest these issues may be reflective not only of a greater burden carried by African American women but also of difficulties dealing with the health system (Porter et al., 2006). For European American women greater distress over symptoms that continue from breast cancer treatment were more indicative of negative mood states (Porter et al., 2006). No differences between

groups were noted in the effects of religious participation or social support. Using cognitive reframing was much more important in the African American participants in ameliorating negative emotions. According to the authors this finding is related to the identified propensity (Bower et al., 2005) of African American women to be able to find meaning in adversity (Porter et al., 2006).

From the literature review and from the studies that did not report statistically usable data there were indications of a difference in the experience of women of different races in long-term survival. The failure of this meta- analysis means that the support for the differences found in the literature was limited. Where the effect sizes could be calculated the findings suggest that differences between African American and European American long-term breast cancers survivors were observable in clinical, social and economic dimensions. What was most surprising was that when the general participant population was compared to the general US population there were no differences, yet where there was the possibility of comparison of African American and European American survivors there was a distinct and noticeable difference with a large effect size.

The secondary questions of the moderating effect of SES and age on the results could not be answered due to lack of data to answer the primary question. While data were available to analyze the sub domains of HRQOL in the SF-36 no difference from population norms was apparent when the participant population in total was compared to the US population norms for the total population. It was impossible to compare different instruments to see if there was an effect size variation for different instruments in the same population. None of the secondary questions proposed were able to be addressed.

Implications of the Findings

While many researchers included African American women in their populations, there was almost no reporting of results separately. It is possible that no difference was found so none was reported, although noting the lack of difference would be appropriate. Some difference would have been predicted based on both qualitative and quantitative findings and literature that did not constrain the population to long-term survival (Ashing-Giwa, Padilla, Tejero, Kraemer, et al., 2004, Bourjolly, et al, 1999; Bowen et al., 2007; Deimling, et al., 2003; Paskett et al., 2008). There were reports where small but clinically observable differences between African Americans and European Americans were noted (Paskett et al., 2008; Ye et al., 2012).

Studies that did not report differences sometimes commented on the difference in quality of life for different racial backgrounds. Ganz (2003 p4190) said "better quality of life was significantly associated with being African American" as compared to European American. Chen(2005), who did report different statistics with a negative and medium to large effect size, noted that African American women were more likely to have physical, physical role and mental health impacts on quality of life that were clinically different to European American women. Trimble (1997) who again reported differences with effect sizes in the moderate range commented that race did not impact quality of life.

In a retrospective study based around a clinical trial of Letrozole in long-term early-stage breast cancer patients (Moy et al., 2006) it was noted (p. 1640) that the action of the drug was different in minorities in that it did not promote disease free survival. This action was thought to be related to how the drug acts on genetic patterns that were

observed in different minority populations. This hypothesis supports the need for research that distinguishes the differences for minority women and reports the data to allow treatment and care decisions to be made based on the needs of the women involved. Moy identified these differences, but the published paper did not report results by race just for minority women in total.

Even if no differences were observed between African American and European American women in survival research, because there were a number of contradictory findings in the area, having access to the data would allow meta-analysis. An attempt was made to contact 47 report authors where data appeared to have been collected, but not reported, or where the reporting was only at the highest population level. Two authors responded positively but were unable to provide data.

The proportion of African Americans in the study population was relatively small, so it was possible that that the researchers did not consider it important to report the results separately. I am not the first to note the small number of African American participants in breast cancer research studies. Ashing-Giwa and Ganz (1997) executed a qualitative study of African American women and breast cancer. This study was in response to their observation that the numbers of minority women included in breast cancer survival studies was too small to be able to draw conclusions (Ashing-Giwa & Ganz, 1997). Twelve studies of the 22 reported racial breakdown with African American's accounting for 8.12% of the study population, if the two African American only studies are removed the African American participant percentage falls to 6.12% or

about half of the 12% calculated in the total survivor population. It was easy to see why results would get lost in the much larger European American numbers.

Publication bias is always an issue that must be considered in a meta-analysis (Lipsey & Wilson, 2001) and the failure to find suitable studies must be considered potentially as symptom of publication bias where no statistically significant findings were being published (Ellis, 2010) or as a reflection of the state of minority research in psychology (Hartmann et al., 2013). The publication of material that focused awareness on health disparities between European Americans and American Ethnic Minorities by the Department of Health and Human Services in 2001 and a change to APA guidelines in 2003 emphasized the need for psychological research with ethnic minorities. These publications might have been expected to prompt a change in the focus on ethnic minorities (Hartmann et al., 2013). Of the nine reports that did not identify their participant by race seven were older than 2003 and one of those was the dissertation. Conversely 12 did identify racial background of participants, and seven were newer than 2003, and 3 of those were dissertations.

The source of the reports for this analysis does reflect one trend that Hartmann et al., (2013) pointed out; the greater publication of psychologically oriented minority focused research in health and medical journals. All of the non-dissertation reports of studies were published in what could arguably be considered medical and health journals see Appendix A for details. Finally, the lack of separate reporting may be directed from editorial policy dictated by the same subtle bias or simply based on required reporting approaches and space requirements. Without input from researchers and editors it was

impossible to know but opens up and interesting research question as to why the data were not reported separately.

The small numbers of African American participants is not a new issue in Cancer related research although it was obvious in this study. Attempts to develop a culturally appropriate and sensitive recruitment strategy (Ashing-Giwa, 1999b) met with limited success. An attempt to develop minority focused research design (Ashing-Giwa, 2005a) was more successful (Ashing-Giwa, Padilla, Tejero, & Kim, 2004). This study introduced a non-standard set of HRQOL instruments and failed to report statistics that could be combined in this meta-analysis.

Initial concern over the inclusion of research of different quality (DeCoster, 2004; Ellis, 2010; Lipsey & Wilson, 2001) proved to be relatively irrelevant to this study as there was not enough research to conduct the meta-analysis. Studies were coded by type of research conducted and showed that the quality of research did not matter; the data were not reported in a way that could enable the analysis.

Implications for Social Change

In might be expected with a failure of the research to come to definitive conclusions that there would be little support for the social change agenda, in fact, the failure reinforces the need for greater knowledge about the long-term consequences of breast cancer for African American women. That there was so little separate reporting of findings in the studies and that the participation rates were so small in the studies that were found means that studies that were based primarily on the European American population should not be generalized to the African American population automatically.

Even though on comparison the differences between the total participant population and the total norm population did not show effect sizes big enough to be observed, the small amount of data from multiple sources suggests that there was a difference, and it still needs to be examined and defined.

Calls of researchers for higher participation from minorities, especially African Americans in biopsychosocial research (Ashing-Giwa, Padilla, Tejero, & Kim, 2004; Ashing-Giwa, 2005a; Hartmann et al., 2013) are more important than ever as the makeup of the US population changes (Hartmann et al., 2013). It is also more relevant as research emphasizes that race can have impacts in the type of treatment and the social and psychological impact of chronic disease (Krieger & Sidney, 1996). Even though it proved impossible to integrate the current research, there were enough indications from what was found to provide support for further inquiry and for continued focus on changing the way participants are recruited into studies to ensure appropriate minority involvement.

Recommendations for Action

It was disappointing and frustrating that after an extensive search, and despite the amount of research being conducted, and the intersection of two hot topics, Breast Cancer Survival and Minority experience of illness, I was forced to admit that the quality of research was questionable. Some of the most published researchers failed to report statistics on dispersion in their findings. Other researchers adjusted their data without a clear indication of the manipulations they had executed. In reality these actions suited the purposes of the study, report or journal, but made inclusion of the data into a meta-

analysis, or replication of the work unlikely. The failure to report minority statistics, even when reporting that there were minority participants in the study, and in some cases noting differences in text, provided an object lesson in good reporting practices.

It was hard to make a failure into a call for change. But I believe that this requires just that. The findings of this research would have been important if the summary showed a difference between the African American survivors and the European American survivors. It would have been important if no difference was apparent. It was just as important that identification of the issues with the data as well the need for further diligence in recruitment of participants and the reporting of findings be highlighted and published.

Recommendations for Further Study

The primary question of the dissertation requires further investigation. Finding out if there is a difference in HRQOL for African American and European American long-term BCS needs to be done on a large enough and geographically diverse enough participant base, with an oversampling of African American participants to try to determine a detailed enough answer to support action. Likewise, information on age and SES to enable the examination of these moderators is still required.

Many authors in this area have mentioned the importance of not only looking at overall HRQOL but also of understanding the how the underlying domains were distinguished (Cella et al., 1993; Chalmers, 2007; Osoba et al., 1997; Ringdal & Ringdal, 1993; Schag et al., 1991). This lower level of data of physical, psychological, social and spiritual domains also needs to be examined.

The proliferation of instruments in measuring HRQOL, and the differing operational definitions of the concepts embodied in the instruments (Lipscomb et al., 2004b; Zebrack, 2004) made the combination of data from different studies difficult. Meta-analysis requires that the effects being combined arguably represent the same concept (Cooper et al., 2009; Lipsey & Wilson, 2001). Little work was found that compares the instruments, and few of the instruments had norms available for BCS and matched populations. This valuable way of looking at the experience of women would be more powerful when the kind of information available about more established measurement approaches is available.

There is an opportunity to use evolving technology in support of developing information from data. The development of databases of research data that would allow the integration across published and unpublished data opens up the possibility for research to be consolidated more easily. This kind of database would provide the opportunity for more effective synthesis and analysis using techniques of data-mining and data- analytics that were beyond the scope of this dissertation and not possible without a repository of data.

A cost/benefit analysis of initiating a curated or non-curated Database for the housing of research data in this area needs to be examined. Databases and data sets already exist for research (University of Illinois, 2013) and the "value of curated databases lies in the organisation, the annotation and the quality of the data they contain" (Buneman, 2009 abstract). Non-curated databases are becoming more possible and are less expensive to maintain, but may allow the issue of non-availability of data, except in

summarized or otherwise manipulated forms, to be overcome (Cannon, Howell, Goddard, & De Schutter, 2002).

There is a further need to explore how to increase minority involvement in research. An exploration of the use of social media may provide access to previously under-represented minority participants. Where computers may not have reached into minority populations, cell phones and social media may have greater reach (Chou, Hunt, Beckjord, Moser, & Hesse, 2009).

In Conclusion

Reflection on the Process

While it is more likely that a qualitative researcher will include their reflections on the process of the dissertation, this has been a journey. I made progress through Chalmers' article on SIDS deaths (Chalmers, 2007) and other medical problems hidden by the proliferation of research and unearthed by meta-analysis that provided the insight into the power of integrating research from many studies. The path was illuminated by Krieger's understanding of race and its impacts on health and well-being in the United States (Kreiger, 1990), which opened up my understanding of the importance of race on the perception of mental and physical health. This was a journey from frustration with the approaches to reporting of research and the inclusion or lack of inclusion and distinction among participants, through the newness and therefore lack of rigor in HRQOL instrumentation, and the unavailability of raw data. Even though the meta-analysis failed, the dissertation added to the knowledge base. This study helped identify the bigger problem of how we can integrate the data from the many researchers who are

working across the field in such a way as to be able to cross pollinate and inform future research. It suggests further work to find a way to make it possible to turn data more effectively into information would be useful.

Conclusion

The meta-analysis failed through lack of available granular data. There was enough evidence in the literature, from qualitative and quantitative studies and where there were enough data to make a comparison, to continue to investigate the difference between African American and European American long-term BCS. This evidence supports a continued hypothesis that current data, which do not break out racial or socioeconomic differences, mask distinctions that would be visible when examined with data of deep enough granularity. There was evidence of underrepresentation of African American women in this research and that even when they were included in the research their data were not reported in such a way as to make differences visible.

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Appendix A: Process Documentation

This Appendix contains additional information from the search, coding and analysis sections of the process followed in this dissertation. The working of the analysis and the development of the forest plots, a spreadsheet of the searches and retrieval from each database with the actual syntax used for each data search are separately available on request.

Support Documentation

Search and Coding Documentation

The following tables provide further documentation from the process steps conducted in the search.

Table A1

Search by Step Numbers in Process

Running total	Number	Description
	8699	Retrieved documents from searches
4357	4342	Duplicates
4324	33	Rejected from federal government documents
4310	14	Not English
3168	1142	Wrong stage of cancer, too advanced breast cancer, or related to prevention or treatment
1527	1641	Drug trials, not breast cancer, not cancer at all, other quality of life studies of non-illness populations
1429	98	Directly related to instruments and validation
1411	18	Reviews and meta-analysis

Running total	Number	Description
1373	38	Qualitative studies
1181	192	Background interest
	1181	Move to next review process. - read abstracts.
542	639	rejected on reading abstracts
213	329	rejected on full text pull
		rejected of first coding pass (60 Background interest, 212 meta-analysis, review, and instrument related, remainder duplicates
75	138	and wrong timeframe)
	75	retained in plan 12.3.13
78	3	added from bibliographies and references 12.3.13
		non-standard instruments, population included larger proportion
60	18	of recent survivors than initially identified
58	2	only one study uses the instrument so comparisons not possible.

Table A2

Code Page

Column head	type	values	Information
search sequence	N:A	reference search control. Sequence number is made of combination of search arguments and search retrieval source.	See Search control worksheet.
document status	N	1= returned in search, 2= relevant to study , 3= background information, 4= possible study for inclusion, 5= study for coding, 6= coded, 7= invalid or withdrawn, 8 = examined, not included	
In bib software	A	Yes/ No	
Full text	A	Yes/ no	
information type	N	1=Background;2=Empirical evidence;3=Both;4=This document was irrelevant	What type of information was contained in this document?
type of evidence	N	1= Descriptive;2= Evaluation of an interventions;3=Both;4 = Other	If empirical, what type of empirical evidence did this document contain?
type of background	N	1= Descriptions of previous research;2=Issues in program implementation;3= Arguments for and/or against; 4= Review of previous research; 5= methods information 6=Other	If background, what type of background information did this document contain?
Record ID	N	Sequential reference number assigned starting with 1000	
Retrieval Date	dd/mm/yy	Date of retrieval from database	
Rejection Reason	alpha	NQ = not quantitative, T = related to treatment, S= wrong stage of cancer, D = not long-term survivors, R = not report of study, P = prevention	

Table A3

Final Retrieval of Documents in Last Stage of Coding

Study ID	Title	Initial Author	Date Published	Journal
1387	Quality of life of African-American and white long term breast carcinoma survivors.	Ashing-Giwa	1999	Cancer
19	Quality of life and psychosocial outcomes in long-term survivors of breast cancer: A focus on African-American women	Ashing-Giwa	1999	Journal of Psychosocial Oncology
1522	Disparities in HRQOL of cancer survivors and non-cancer managed care enrollees	Clauser	2008	Health Care Financing Review
1966	Depressive Symptoms and Health-Related Quality of Life in Breast Cancer Survivors.	Reyes-Gibby	2002	Journal of Women's Health
2024	Long-term adjustment of survivors of early-stage breast carcinoma, 20 years after adjuvant chemotherapy	Kornblith	2003	Cancer
2169	All's Well That Ends Well? Quality of Life and Physical Symptom Clusters in Long-Term Cancer Survivors Across Cancer Types.	Zucca	2012	Journal of Pain and Symptom Management
1904	The quality of life of African American women with breast cancer.	Northouse	1999	Research in Nursing & Health
1978	Breast cancer in African American women: Validation of a quality of life instrument.	Rowley/	2000	Dissertation
1040	Personality, coping, and quality of life in early stage breast cancer survivors	Caloudas	2011	Dissertation
1283	Worry of recurrence in breast cancer survivors	Rothrock	2003	Dissertation
2077	An Exploratory Analysis of Fear of Recurrence among African-American Breast Cancer Survivors.	Taylor		International Journal of Behavioral Medicine

Study ID	Title	Initial Author	Date Published	Journal
2027	Benefits from an uncertainty management intervention for African–American and Caucasian older long-term breast cancer survivors.	Mishel		Psycho-Oncology
2031	Predicting Negative Mood State and Personal Growth in African American and White Long-Term Breast Cancer Survivors.	Porter		Annals of Behavioral Medicine
2130	Relationship between quality of life and mood in long-term survivors of breast cancer treated with mastectomy	Weitzner		Supportive Care in Cancer:
1148	Breast cancer survivorship: Contributing factors for special populations	Jabson		Dissertation
1692	Quality of life and lymphedema following breast cancer.	Heiney		Lymphology
2035	Quality of life among older survivors of breast cancer.	Sammarco		Cancer Nursing
2036	Quality of life of breast cancer survivors: a comparative study of age cohorts	Sammarco		Cancer Nursing
1145	Social support, God locus of health control, and quality of life among African American breast cancer survivors	Huff		Dissertation
222	Symptom distress, spirituality, and quality of life in African American breast cancer survivors.	Leak		Cancer Nursing
1161	Describing psychosocial risk factors in breast cancer diagnosis and survivorship	Keating		Dissertation
1799	Quality of life and breast cancer survivors. Psychosocial and treatment issues.	Lee	1997	Cancer Practice
1362	Quality of life of long-term survivors of breast cancer and lymphoma treated with standard-dose chemotherapy or local therapy.	Ahles	2005	Journal of Clinical Oncology.

Study ID	Title	Initial Author	Date Published	Journal
584	Age at Diagnosis and Quality of Life in Breast Cancer Survivors.	Cimprich	2002	Cancer Practice
1570	An evaluation of the quality of life among long-term survivors of breast cancer.	Dow	1996	Breast cancer research and treatment
1446	Association between current lifestyle behaviors and health-related quality of life in breast, colorectal and prostate cancer survivors.	Blanchard	2004	Psychology and health
1392	A cross-cultural validation of patient-reported outcomes measures: a study of breast cancers survivors.	Ashing-Giwa	2013	Quality of Life Research
163	Surviving cancer: A comparison of 5-year disease-free breast cancer survivors with healthy women.	Helgeson	2005	Psycho-Oncology.
277	Breast cancer survivors' health-related quality of life: racial differences and comparisons with noncancer controls.	Paskett	2008	Cancer
282	Relationship of Optimism-Pessimism and Health-Related Quality of Life in Breast Cancer Survivors.	Petersen	2008	Journal of Psychosocial oncology
1052	Long-term quality of life assessment in post-menopausal women with primary breast cancer	Chen	2005	Dissertation
1056	Functional Impairment and the Economic Consequences of Female Breast Cancer	Chirikos	2002	Women and health
1328	Long-term survivorship in breast cancer: Quality of life at five years and beyond	Trimble	1997	Dissertation
1364	Lymphedema and quality of life in breast cancer survivors: the Iowa Women's Health Study.	Ahmed	2008	Journal of clinical oncology
1452	Quality of life of younger breast cancer survivors: persistence of problems and sense of well-being.	Bloom	2004	Psycho-Oncology

Study ID	Title	Initial Author	Date Published	Journal
1458	Health-related quality of life in breast cancer survivors of different sexual orientations.	Boehmer	2012	Quality of Life Research
1468	Fatigue in long-term breast carcinoma survivors - A longitudinal investigation	Bower	2006	Cancer
1521	Quality of life for women diagnosed with breast carcinoma in situ	Claus	2006	Journal of clinical oncology
1878	Invariance Testing of the SF-36 Health Survey in Women Breast Cancer Survivors: Do Personal and Cancer-related Variables Influence the Meaning of Quality of Life Items?	Mosewich	2013	Social Indicators Research
2006	Then and now: quality of life of young breast cancer survivors.	Bloom	2012	Psycho-Oncol 2004
3001	Five years later: a cross-sectional comparison of breast cancer survivors with healthy women	Tomich	2002	Psycho-oncology
10	Frequent Search for Sense by Long-Term Breast Cancer Survivors Associated with Reduced HRQOL.	Andersen	2008	Women & Health
71	Complementary and alternative therapies among very long-term breast cancer survivors	Carpenter	2009	Breast cancer research and treatment
1565	Health-related quality of life, age, and comorbidity in breast cancer survivors 1 to 12 years post-treatment.	Dhingra	2002	Dissertation
1630	Breast cancer in younger women: reproductive and late health effects of treatment.	Ganz	2002	Journal of the national cancer institute
1713	Quality of Life in Long-Term Breast Cancer Survivors.	Hsu	2013	J Clin Oncol. 2013 Aug 26. [Epub ahead of print]
1826	The roles of herbal remedies in survival and quality of life among long-term breast cancer survivors - results of a prospective study.	Ma	2011	BMC Cancer

Study ID	Title	Initial Author	Date Published	Journal
1879	Associations between lifestyle factors and quality of life among older long-term breast, prostate, and colorectal cancer survivors.	Mosher	2009	Cancer
1881	Clinical outcomes of ethnic minority women in MA.17: a trial of letrozole after 5 years of tamoxifen in postmenopausal women with early stage breast cancer	Moy	2006	Annals of Oncology
1883	Efficacy, toxicity, and quality of life in older women with early-stage breast cancer treated with Letrozole or placebo after 5 years of tamoxifen: NCIC CTG intergroup trial MA.17.	Muss	2008	Journal of clinical oncology
1935	Social capital, social support, and quality of life among long-term breast cancer survivors.	Petersen	2008	Journal of Psychosocial Oncology
2030	Functional status of long-term breast cancer survivors: demonstrating chronicity	Polinsky	1994	Health & social work
2117D	Exercise in breast cancer survivors: Predicting quality of life with the cognitive-appraisal model of stress and coping.	Wagner	2006	Dissertation
2113	Health-related quality of life of African American breast cancer survivors compared with healthy African American women.	Von Ah	2012	Cancer Nursing
143	Quality of Life in Long-Term, Disease-Free Survivors of Breast Cancer: a Follow-up Study.	Ganz	2002	Journal of Clinical Oncology
75	Quality of life of 5-10 year breast cancer survivors diagnosed between age 40 and 49.	Casso	2004	Health & Quality of Life Outcomes

Study ID	
Title	
Initial Author	
Date Published	
total subjects	
African American subjects	
European American subjects	
Other subject	
Study date	
Methodology	
geography	
mean time since diagnosis	
instrument	
statistics reported	
notes on article	

Figure A1. Coding form used to collect data.

Table A4

Instruments Used in Rejected Reports

Instrument	Number	Reports
EORTC	4	Clauser et al., 2008; Kornblith et al., 2003; Reyes-Gibby et al., 2012; Zucca et al., 2012
FACTB	2	Northouse et al., 1999; Rothrock, 2003; Rowley, 2000; Taylor et al., 2012
POMS	2	Mishel et al., 2005; Porter et al., 2006 Both reports of the same study
QLI CV III	3	Sammarco, 2003, 2009; Weitzner, Meyers, Stuebing, & Saleeba, 1997
QOLBC	2	Heiney et al., 2013; Jabson, 2010
SF36	14	Ahmed, Prizment, Lazovich, Schmitz, & Folsom, 2008; Ashing-Giwa & Rosales, 2013; Blanchard et al., 2004; Bower et al., 2006; Claus, Petruzella, Carter, & Kasl, 2006; Ma, Carpenter, Sullivan-Halley, & Bernstein, 2011; Mosewich, Hadd, Crocker, & Zumbo, 2013; Moy et al., 2006; Muss et al., 2008; Paskett et al., 2008; Polinsky, 1994; Tomich & Helgeson, 2002; Von Ah et al., 2012; Wagner, 2006

Table A5

Dissertations and Sources that Exited the Coding Process

Authors	*Pub Date*	*Title*	*Source*
Huff	*2013*	*Social support, God Locus of Health Control, and quality of life among African American breast cancer survivors*	*(D.H.A.). Central Michigan University, United States -- Michigan.*
Chen.	*2005*	*Long-term quality of life assessment in post-menopausal women with primary breast cancer*	*(M.Sc.). Queen's University at Kingston (Canada), Canada.*
Dhingra	*2002*	*Health-related quality of life, age, and comorbidity in breast cancer survivors 1 to 12 years post-treatment*	*(Ph.D.). Illinois Institute of Technology, United States -- Illinois.*
Keating	*2007*	*Describing psychosocial risk factors in breast cancer diagnosis and survivorship*	*(Ph.D.). Loyola University Chicago, United States -- Illinois.*
Trimble	*1997*	*Long-term survivorship in breast cancer: Quality of life at five years and beyond*	*(Ph.D.). The Ohio State University, United States -- Ohio.*
Petersen, D.	*2008*	*Social Capital, Social Support and Long-Term Quality of Life*	*(PhD). University of California, Berkley, Berkley.*

Table A6

Reports that Exited Coding Process with Publication Sources

Authors	Pub Date	Title	Source	Publisher
Dow, K. H., Ferrell, B. R., Leigh, S., Ly, J., & Gulasekaram, P.	1996	An evaluation of the quality of life among long-term survivors of breast cancer.	Breast Cancer Res.and Treat.	Springer
Carpenter, C. L., Ganz, P. A., & Bernstein, L.	2009	Complementary and alternative therapies among very long-term breast cancer survivors.	Breast Cancer Res.and Treat.	Springer
Leak, A., Hu, J., & King, C. R.	2008	Symptom Distress, Spirituality, and Quality of Life in African American Breast Cancer Survivors.	Cancer Nursing	Lippincott Williams and Wilkins
Lee, C. O.	1997	Quality of life and breast cancer survivors. Psychosocial and treatment issues	Cancer Practice	Wiley
Cimprich, B., Ronis, D. L., & Martinez-Ramos, G.	2002	Age at diagnosis and quality of life in breast cancer survivors.	Cancer Practice	Wiley
Mosher, C. E., Sloane, R., Morey, M. C., Snyder, D. C., Cohen, H. J., Miller, P. E., & Demark-Wahnefried, W.	2009	Associations between lifestyle factors and quality of life among older long-term breast, prostate, and colorectal cancer survivors.	Cancer	Wiley
Ashing-Giwa, K., Ganz, P. A., & Petersen, L.	1999	Quality of life of African-American and white long term breast carcinoma survivors.	Cancer	Wiley
Casso, D., Buist, D. S., & Taplin, S.	2004	Quality of life of 5-10 year breast cancer survivors diagnosed between age 40 and 49.	Health and quality of life Outcomes	Biomed central

Authors	Pub Date	Title	Source	Publisher
Ahles, T. A., Saykin, A. J., Furstenberg, C. T., Cole, B., Mott, L. A., Titus-Ernstoff, L., … Silberfarb, P. M.	2005	Quality of life of long-term survivors of breast cancer and lymphoma treated with standard-dose chemotherapy or local therapy.	Journal of Clinical Oncology	Am. Soc. Clinical Oncology
Hsu, T., Ennis, M., Hood, N., Graham, M., & Goodwin, P. J.	2013	Quality of life in long-term breast cancer survivors.	Journal of Clinical Oncology	Am. Soc. Clinical Oncology
Ganz, P. A., Greendale, G. A., Petersen, L., Kahn, B., & Bower, J. E.	2003	Breast Cancer in Younger Women: Reproductive and Late Health Effects of Treatment.	Journal of Clinical Oncology	Am. Soc. Clinical Oncology
Ashing-Giwa, K.	1999	Quality of life and psychosocial outcomes in long-term survivors of breast cancer: A focus on African-American women.	Journal of Psychosocial Oncology	Taylor and Francis Routledge
Petersen, L. R., Clark, M. M., Novotny, P., Kung, S., Sloan, J. A., Patten, C. A., … Colligan, R. C.	2008	Relationship of Optimism-Pessimism and Health-Related Quality of Life in Breast Cancer Survivors.	Journal of Psychosocial Oncology	Taylor and Francis Routledge
Bloom, J. R., Stewart, S. L., Oakley-Girvan, I., Banks, P. J., & Shema, S.	2012	Quality of life of younger breast cancer survivors: persistence of problems and sense of well-being.	Psycho-Oncology	Wiley
Helgeson, V. S., & Tomich, P. L.	2005	Surviving cancer: A comparison of 5-year disease-free breast cancer survivors with healthy women.	Psycho-Oncology	Wiley
Chirikos, T. N., Russell-Jacobs, A., & Jacobsen, P. B.	2002	Functional Impairment and the Economic Consequences of Female Breast Cancer.	Women & Health	Taylor and Francis Routledge

Analysis Support Documentation

Table A7

Racial Background of Participants in Studies Included in Analysis

Initial Author	Date Published	total subjects	African American subjects	European American subjects	Other subject
Ashing-Giwa	1999	278	117	161	0
Bloom	2012	312	18	227	67
Carpenter	2009	371	0	335	36
Chen	2005	3329	105	3224	
Cimprich	2002	105	9	96	0
Ganz	2003	577	67	405	105
Hsu	2013	285	8	214	63
Keating	2007	106	0	106	
Lee	1997	100	3	88	9
Trimble	1997	226	21	205	
Total		5689	348	5061	280
Percentage			6.12%	88.96%	4.92%
Huff	2012	94	94	0	0
Leak	2008	30	30		
Total		124	124		
Grand total		5813	472	5061	280
Percentage			8.12%	87.06%	4.82%

Table.A8

Participant Numbers where Breakdown of Racial Background Not Provided

Initial Author	Date Published	Total Subjects	Comment
Ahles	2005	425	white only identified
Casso	2004	216	Caucasian and other
Chirikos	2008	105	maximize representation of racial minorities but never gives breakdown
Dhingra	2002	257	no racial identification
Dow	1996	294	Only identifies Caucasian
Helgeson	2005	267	92 % were Caucasian
Mosher	2009	321	Have breakdown of total sample but not BC sample
Petersen	2008	255	No racial breakdown identified
Petersen	2008	387	white/ other
	Total	2527	

Table A9

Instruments Used by the Coded Reports

Instrument	Number	Citation
FACT B	1	Caloudas, 2011(not included in analysis)
QLI-CVIII	4	Huff, 2013; Keating, 2007; Leak, Hu, & King, 2008; Lee, 1997
QOL CS	3	Ahles et al., 2005; Cimprich, Ronis, & Martinez-Ramos, 2002; Dow et al., 1996
SF 12	1	Boehmer, Glickman, Milton, & Winter, 2012
SF- 36	14	Bloom et al., 2004; Bloom, Stewart, Oakley-Girvan, Banks, & Shema, 2012; Carpenter et al., 2009; Chen, 2005; Chirikos, Russell-Jacobs, & Jacobsen, 2002; Dhingra, 2002; P A Ganz et al., 2002; Patricia A. Ganz, Greendale, Petersen, Kahn, & Bower, 2003; Helgeson & Tomich, 2005; Hsu, Ennis, Hood, Graham, & Goodwin, 2013; Mosher et al., 2009; D. Petersen, 2008; L. R. Petersen et al., 2008; Trimble, 1997;
With CARES-SF	3	Ashing-Giwa, Ganz, & Petersen, 1999; Ashing-Giwa, 1999; Casso, Buist, & Taplin, 2004

Support documentation for SF-36 subscale analysis. The following are the forest plots of the analysis of the studies that contain subscale data. Chen (2005) provided separate data for African American and European American participants, although the African American population sample is small compared to the European American participant pool. Bloom (2012) provided data on the same sample in two different time periods; 5 and10 years post diagnosis, these studies can be considered as distinct even though the same population was studied. All population norms in the following discussion were retrieved from SF-36.org (n.d.).

Physical function SF-36 1990

Study	Sample Size	Mean (95% CI)
Bloom,2012 (5 year)	312	87.37(85.35-89.39)
Bloom,2012 (10 Year)	312	86.22(83.84-88.6)
Chen (EA),2005	3144	77.03(76.19-77.87)
Chen(AA),2005	101	65(59.36-70.64)
Chirikos,2002	105	82.6(78.7-86.5)
Ganz,2003	577	84.3(82.69-85.91)
Helgeson,2005	267	84.77(82.3-87.24)
Mosher,2009	321	73.2(70.99-75.41)
Petersen L.R.,2008	255	58.41(54.67-62.15)
Petersen,D.,2008	387	87.23(85.24-89.22)
Trimble,1997	183	75.8(72.29-79.31)
Summary	5964	78.6(77.36-79.85)
Pop Norm 1990	2474	84.5(83.6-85.4)

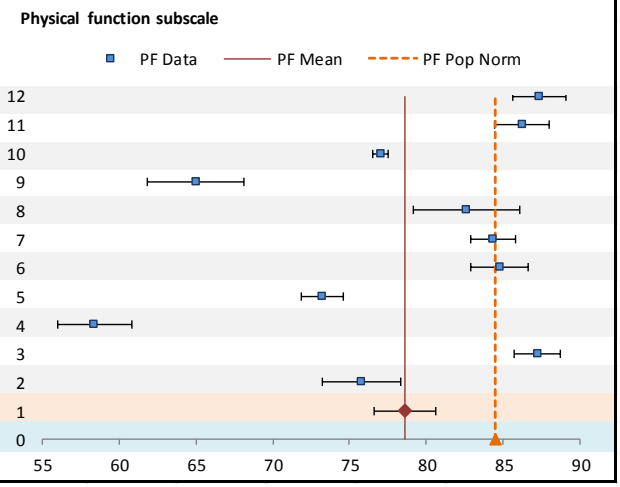

Figure A2. Physical Function subscale analysis with Population norm for 1990 general population.

The Physical Function subscale of the SF-36 Is composed of 10 items. Low functioning on this subscale is defined as "limited a lot in performing all physical activities including bathing or dressing" (Ware & Sherbourne, 1992, p. 475). High endorsement of this subscale is defined as "Performs all types of Physical activities including the most vigorous without limitations due to health" (Ware & Sherbourne,

1992, p. 475). The 5.9 point difference between the mean of the analysis and the population norm suggested that there was an observable difference in clinical, social or economic status of breast cancer patients when compared to the population norm. Three studies (Chen, 2005 (EA); Mosher et al., 2009; Trimble, 1997) had differences that expected to be observable while most of the other studies were closer to the population mean and would not be expected to have observable differences.

Physical Role SF-36 1990

Study	Sample Size	Mean (95% CI)
Bloom,2012 (5 year)	312	82.05(78.36-85.74)
Bloom,2012 (10 Year)	312	80.77(76.91-84.63)
Chen (EA),2005	3142	82.6(81.51-83.69)
Chen(AA),2005	100	72(64.24-79.76)
Chirikos,2002	105	70.2(62.13-78.27)
Ganz,2003	577	79.2(76.35-82.05)
Helgeson,2005	267	81.9(77.83-85.97)
Mosher,2009	321	74.5(70.69-78.31)
Petersen L.R.,2008	255	50.64(45.27-56.01)
Petersen,D.,2008	387	80.33(76.87-83.79)
Trimble,1997	182	68.7(62.85-74.55)
Summary	5960	75.22(70.91-79.54)
Pop Norm 1990	2474	81.2(79.87-82.53)

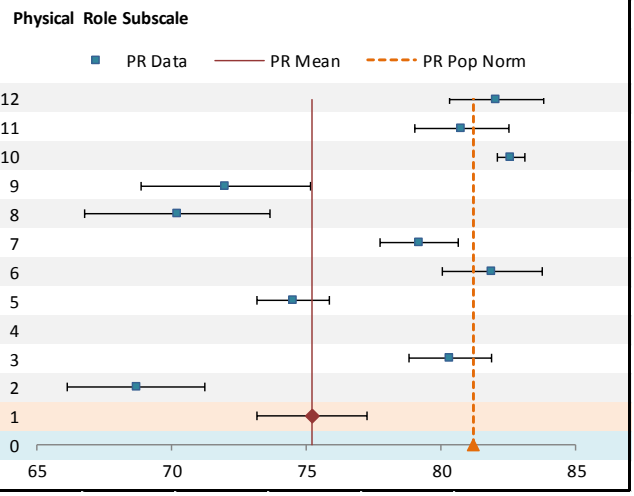

Figure A3. Physical Role subscale analysis with Population norm for 1990 general population.

The Physical Role subscale is drawn from 4 items on the SF36 questionnaire and sets out to measure where the respondent's roles are limited due to the physical impacts of their illness. The low end of this subscale is defined as "Problems with work or other daily activities as a result of Physical Health" (Ware & Sherbourne, 1992, p. 475) and the high end of this spectrum is defined as "No problems with work or other daily activities as a result of Physical health, past 4 weeks" (Ware & Sherbourne, 1992, p. 475). The difference between the analysis mean and the population norm in this subscale of 5.98 points suggested an observable difference between the long-term BCS and the general

population. Four of the studies (Chen (African American), 2005; Chirikos et al., 2002; Mosher et al., 2009; L. R. Petersen et al., 2008; Trimble, 1997) had a mean that was more than 5 points different from the norm and would predict observable differences in social, economic or clinical functioning.

Body Pain SF-36 1990

Study	Sample Size	Mean (95% CI)
Bloom,2012 (5 year)	312	73.83(71.13-76.53)
Bloom,2012 (10 Year)	312	72.15(69.62-74.68)
Chen (EA),2005	3159	77.16(76.41-77.91)
Chen(AA),2005	101	71.31(66.21-76.41)
Chirikos,2002	105	72.1(66.76-77.44)
Ganz,2003	577	78.4(76.61-80.19)
Helgeson,2005	267	75.62(72.69-78.55)
Mosher,2009	321	70.5(68.13-72.87)
Petersen L.R.,2008	255	64.09(60.68-67.5)
Petersen,D.,2008	387	71.65(69.36-73.94)
Trimble,1997	184	73.4(69.77-77.03)
Summary	5980	72.92(70.57-75.28)
Pop Norm 1990	2474	75.5(74.57-76.43)

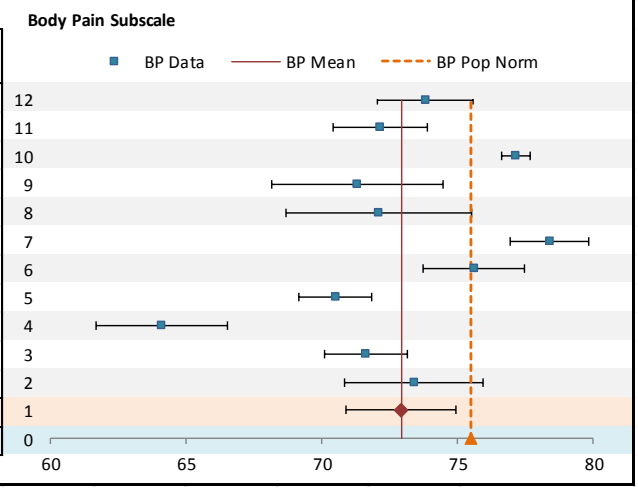

Figure A4. Body Pain subscale analysis with Population norm for 1990 general population.

The Body Pain Subscale is drawn from 2 items in the instrument and ranges from " Extreme and frequent interference with normal social activities due to physical and emotional problems" to " performs normal social activities without interference due to physical or emotional problems, past 4 weeks" (Ware & Sherbourne, 1992, p. 475). In this subscale, the difference between the grand mean and the population norm was less than the 5 point threshold where observable differences would be expected. Only one study (L. R. Petersen et al., 2008) showed a difference from both the analysis mean and the population norms that would suggest observable differences. One study (Ganz et al., 2003) showed a difference of 5.48 points from the summary mean which may indicate observable difference. If the results of the lowest (L. R. Petersen et al., 2008) and highest

(Ganz et al., 2003) means in the study sample were compared, observable difference between the samples on the body pain spectrum should be expected.

General Health SF-36 1990

Study	Sample Size	Mean (95% CI)
Bloom,2012 (5 year)	312	77.79(75.6-79.98)
Bloom,2012 (10 Year)	312	72.48(70.27-74.69)
Chen (EA),2005	3137	76.62(76-77.24)
Chen(AA),2005	100	69.98(66-73.96)
Chirikos,2002	105	73(68.7-77.3)
Ganz,2003	577	72.1(70.39-73.81)
Helgeson,2005	267	79.03(76.52-81.54)
Mosher,2009	321	73.2(71.44-74.96)
Petersen L.R.,2008	255	60.68(57.92-63.44)
Petersen,D.,2008	387	72.71(70.76-74.66)
Trimble,1997	183	69.2(65.84-72.56)
Summary	5956	72.54(70.01-75.08)
Pop Norm 1990	2474	72.2(70.74-73.66)

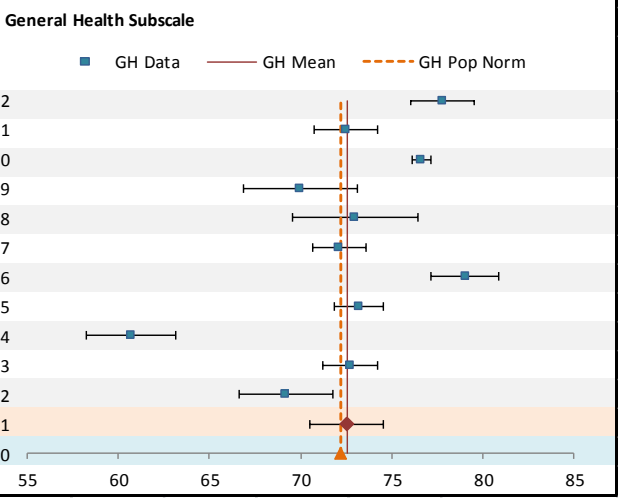

Figure A5. General Health subscale analysis with Population norm for 1990 general population.

General Health perceptions are drawn from 5 questions in the instrument with lower scores meaning that the respondent "Believes personal health is poor and likely to get worse" and higher scores reflecting that the respondent "Believes personal health is excellent" (Ware & Sherbourne, 1992, p. 475).

This subscale is not used in calculating the summary PCS and MCS measures and has been shown to be useful in distinguishing changes in health status in the year preceding administration of the instrument. There is support for this category as being reliable in interpreting this at a group level with drops in the mean value corresponding to self-evaluated declines in health and increases in the mean value corresponding to improvements in overall HRQOL (Ware, n.d.)

In this subscale, the grand mean and the population norm were similar with 0.34 of a point difference in the means. In this subscale there was both a lower score (L. R.

Petersen et al., 2008), where the study mean is 11.86 points lower than the population norm, and two higher scores (Bloom et al.(5+ years), 2012; Helgeson & Tomich, 2005) where there is a greater than 5 point difference from the population norm. All of these would suggest observable differences between the studies and the population. With the spread of 18.4 points from the lowest study mean to the highest, differences in the populations from these studies should be obvious.

Vitality SF-36 1990

Study	Sample Size	Mean (95% CI)
Bloom,2012 (5 year)	312	62.96(60.61-65.31)
Bloom,2012 (10 Year)	312	63.41(61.2-65.62)
Chen (EA),2005	3149	65.66(64.97-66.35)
Chen(AA),2005	101	63.04(59.55-66.53)
Chirikos,2002	105	60.5(56.16-64.84)
Ganz,2003	577	58.1(56.32-59.88)
Helgeson,2005	267	64.18(61.67-66.69)
Mosher,2009	321	61.3(59.24-63.36)
Petersen L.R.,2008	255	52.86(50.3-55.42)
Petersen,D.,2008	387	64.46(62.57-66.35)
Trimble,1997	185	59.9(58.44-61.36)
Summary	5971	61.54(59.2-63.89)
Pop Norm 1990	2474	61.1(60.28-61.92)

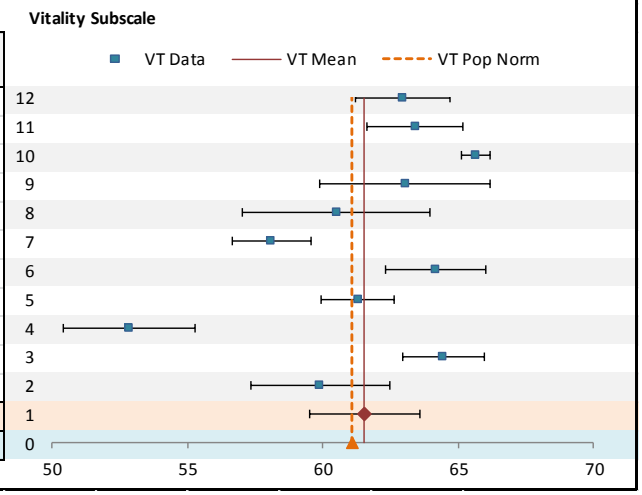

Figure A6. Vitality subscale analysis with Population norm for 1990 general population.

The Vitality subscale is derived from 4 items in the instrument. The lower score for a participant is defined as “Feels tired and worn out all of the time” while high scores describe a respondent who “Feels full of pep and energy all of the time, past four weeks” (Ware & Sherbourne, 1992, p. 475).

The population norm and the analysis mean were 0.44 point different. Most of the studies were within 5 points difference from the mean with only one (L. R. Petersen et

al., 2008) having a greater distance at 8.68 points lower. The distance between the highest (Chen (EA), 2005) and lowest (L. R. Petersen et al., 2008) of the studies was 12.8 points.

Social Function SF-36 1990

Study	Sample Size	Mean (95% CI)
Bloom,2012 (5 year)	312	86.66(84.29-89.03)
Bloom,2012 (10 Year)	312	85.7(83.25-88.15)
Chen (EA),2005	3150	91.37(90.77-91.97)
Chen(AA),2005	100	85.38(80.88-89.88)
Chirikos,2002	105	85.7(80.08-91.32)
Ganz,2003	577	83.9(82.12-85.68)
Helgeson,2005	267	89.6(87.23-91.97)
Mosher,2009	321	90.2(88.25-92.15)
Petersen L.R.,2008	255	75.04(71.81-78.27)
Petersen,D.,2008	387	86.27(84.18-88.36)
Trimble,1997	184	85.4(82.16-88.64)
Summary	5970	86.05(83.38-88.72)
Pop Norm 1990	2474	83.6(82.72-84.48)

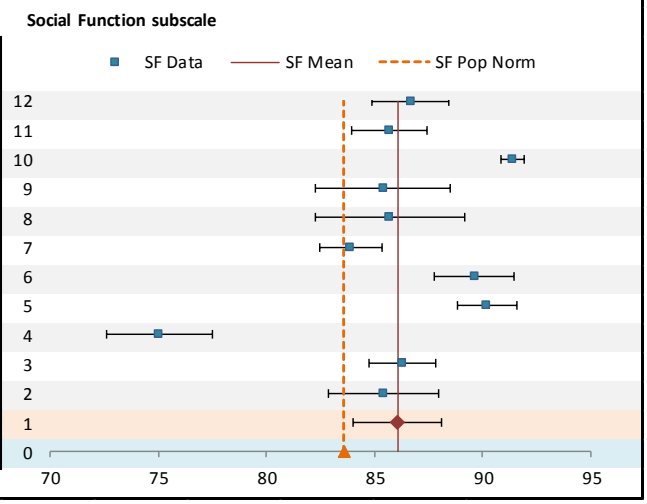

Figure A7. Social Function subscale analysis with Population norm for 1990 general population.

The Social Function subscale is drawn from 2 questions on the instrument. Lower scores reflect "Extreme and frequent interference with normal social activities due to physical and emotional problems" while higher scores reflect a respondent who "Performs normal social activities without interference due to physical or emotional problems, past four weeks" (Ware & Sherbourne, 1992, p. 475).

The analysis mean in this subscale was higher than the population norm by 2.45 points that would not be enough to expect observable differences. The lowest scoring study (L. R. Petersen et al., 2008) was 16.33 points lower than the highest scoring study (Chen (EA), 2005). Both of these studies were greater than5 points different from the analysis mean and the population norm, suggesting observable differences in the social, continuum described by this subscale.

Role Emotional SF-36 1990

Study	Sample Size	Mean (95% CI)
Bloom,2012 (5 year)	312	81.41(77.8-85.02)
Bloom,2012 (10 Year)	312	86.65(83-90.3)
Chen (EA),2005	3115	88.93(88-89.86)
Chen(AA),2005	100	75.5(67.89-83.11)
Chirikos,2002	105	84.1(77.54-90.66)
Ganz,2003	577	79.1(76.3-81.9)
Helgeson,2005	267	86.44(83.06-89.82)
Mosher,2009	321	90.8(88.22-93.38)
Petersen L.R.,2008	255	73.27(68.56-77.98)
Petersen,D.,2008	387	85.01(81.85-88.17)
Trimble,1997	183	79.4(74.37-84.43)
Summary	5934	83.18(80.02-86.34)
Pop Norm 1990	2474	81.3(80-82.6)

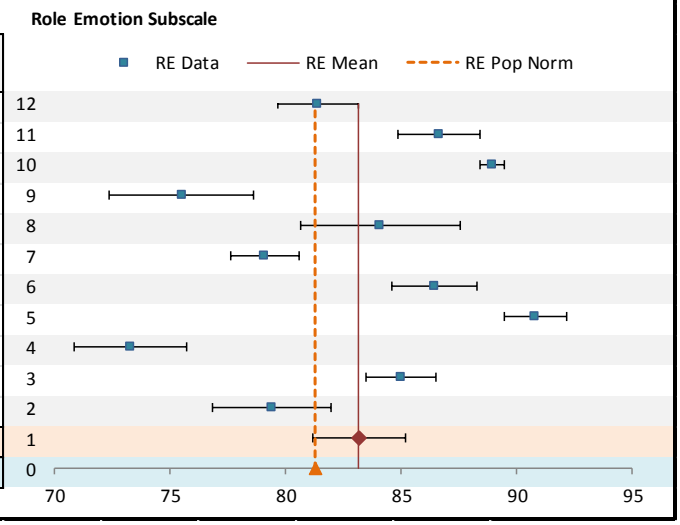

Figure A8. Role Emotional subscale analysis with Population norm for 1990 general population.

The Role Emotional subscale reflects limitations in role performance due to emotional problems. It is drawn from 3 items in the instruments and reflects a spectrum from "Problems with work or other daily activities as a result of emotional problems" to "No problems with work or other daily activities as a result of emotional problems, past four weeks" (Ware & Sherbourne, 1992, p. 475).

The analysis mean was 1.88 points higher than the population norm for the Role emotional subscale. A 17.53 point difference exists between the lowest scoring study (L. R. Petersen et al., 2008) and the highest scoring study (Mosher et al., 2009). There was a greater dispersal of scores on this subscale with 4 studies below the population norm (Chen (African American), 2005; Ganz et al., 2003; L. R. Petersen et al., 2008; Trimble, 1997) and 4 studies scoring more than 5 points higher than the population norm (Bloom et al. (10 year), 2012; Chen (African American), 2005; Helgeson & Tomich, 2005; Mosher et al., 2009).

Mental Health SF-36 1990

Study	Sample Size	Mean (95% CI)
Bloom,2012 (5 year)	312	77.72(75.96-79.48)
Bloom,2012 (10 Year)	312	79.01(77.26-80.76)
Chen (EA),2005	3149	81.44(80.93-81.95)
Chen(AA),2005	101	79.9(76.76-83.04)
Chirikos,2002	105	74.3(70.86-77.74)
Ganz,2003	577	74.9(73.44-76.36)
Helgeson,2005	267	78.85(76.99-80.71)
Mosher,2009	321	85.1(83.75-86.45)
Petersen L.R.,2008	255	72.73(70.3-75.16)
Petersen,D.,2008	387	79.79(78.27-81.31)
Trimble,1997	184	76.6(74.04-79.16)
Summary	5970	78.33(76.3-80.36)
Pop Norm 1990	2474	74.8(74.09-75.51)

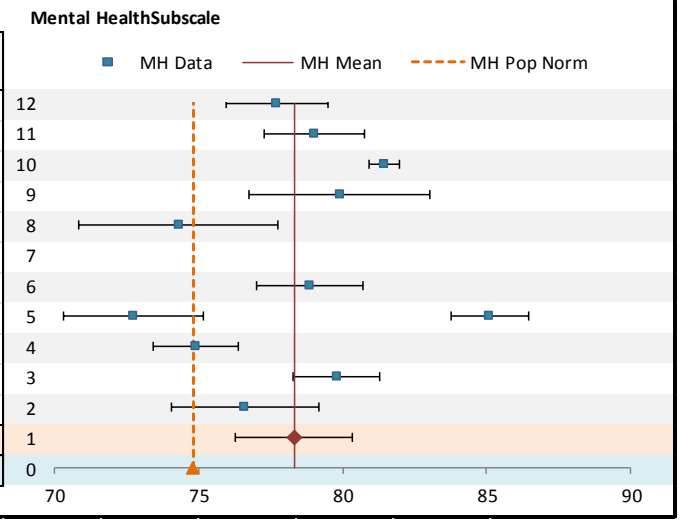

Figure A9. Mental Health subscale analysis with Population norm for 1990 general population.

The Mental Health subscale is drawn from 5 items in the instrument and reflects lower scores that are described as “Feelings of nervousness and depression all of the time” to higher scores described as “ Feels peaceful, happy, and calm all of the time, past four weeks” (Ware & Sherbourne, 1992, p. 475).

In this analysis the general population norm was lower than the mean of the studies included by 3.53 points, less that would indicate observable real world differences. There was a difference between the lowest study mean study (L. R. Petersen et al., 2008) and the highest study mean (Mosher et al., 2009) of 12.37 points that would suggest that there was an observable difference between these two studies. Only one study (Mosher et al., 2009) has a predicted observable difference from the analysis mean in a positive direction, while both populations reported in Chen (2005) as well as Mosher et al. (2009) show a greater than5 point difference in the mean from the population norm.

Only one study (L. R. Petersen et al., 2008) was lower by an amount that would suggest observable difference.

Overall summary effect size, all data. All data that was available to be translated into SMD was analyzed using two different groups of studies. As there is a charge that this data could be comparing different levels of information, the outcome measure can only be used as an indication

Summary of effect sizes for African American and European American long term BCS studies

Study	Sample Size	Effect size SMD (95% CI)
QLI	326	-0.82(-1.06--0.59)
Trimble, 1997 PCS	226	-0.02(-0.47-0.43)
Trimble, 1997 MCS	226	-0.32(-0.77-0.13)
Ashing Giwa, 1999	278	-1.46(-1.75--1.17)
Summary	**830**	**-0.68(-1.19--0.18)**

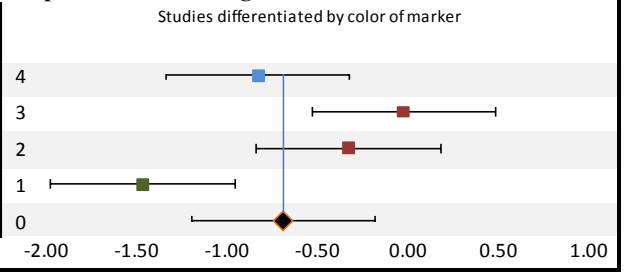

Figure A10. Summary SMD: Ashing – Giwa (1999) and Trimble (1997).

Summary of effect sizes for African American and European American long term BCS studies (2)

Study	Sample Size	Effect size SMD (95% CI)
QLI	326	-0.82(-1.06--0.59)
Trimble, 1997 PCS	226	-0.02(-0.47-0.43)
Trimble, 1997 MCS	226	-0.32(-0.77-0.13)
Ashing Giwa, 1999	278	-1.46(-1.75--1.17)
Chen,2005:PF	3245	-0.5(-0.7--0.3)
Chen,2005:RF	3242	-0.34(-0.54--0.14)
Chen,2005:BP	3260	-0.27(-0.47--0.07)
Chen,2005:GH	3237	-0.37(-0.57--0.17)
Chen,2005:V	3250	-0.13(-0.33-0.07)
Chen,2005:SF	3250	-0.35(-0.54--0.15)
Chen,2005:ER	3215	-0.5(-0.7--0.3)
Chen,2005:MH	3250	-0.11(-0.3-0.09)
Summary		-0.43(-0.62--0.25)

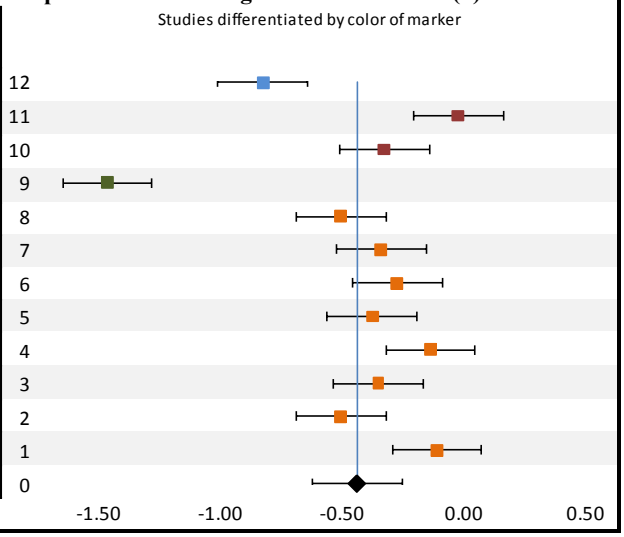

Figure A11. Summary SMD: Ashing – Giwa (1999), Trimble (1997), and Chen (2005).

Curriculum Vitae

Cher de Rossiter
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Education

1994	Macquarie Graduate School of Management, Macquarie University, Sydney, Australia Graduate Diploma in Logistics and Operations Management
1984	Macquarie Graduate School of Management, Macquarie University, Sydney, Australia Advanced Management Program
1977	University of Sydney, Sydney, Australia Bachelor of Arts – Major in Psychology and Philosophy

Teaching experience

2008 – 2014	Clark University, Worchester, MA Professor, College of Professional and Continuing Education (COPACE) MPA/MBA Programs Organizational Behavior and leadership (Warsaw and Lodz (Poland) 2008-2010) (University of Astrakhan, Russia –2011, 2012,2013 MBA program) Change Management (University of Astrakhan, Russia –2011, 2012, 2014 MBA program) Intercultural Communication (University of Astrakhan, Russia - 2012, 2013, 2014 MBA program)
2012	State University of Astrakhan, Astrakhan, Russia (Russian- American Institute) Entrepreneurial Marketing – A hybrid program developed for the University of Astrakhan and delivered to its Entrepreneurial Development program, combining both technologically delivered classes and students' real life companies.
2010-2012	Walden University Graduate assistant Psychology. Assist in delivery of Cognitive and Personality assessment Academic Year in Residence components
2010-2011	Bard College, Annandale NY, Life Long Learning Institute Developed and presented 8 part courses for senior attendees "Understanding your brain can help you change your mind" (2010) "Toolbox for an aging brain" (2011)
1994-1996	IBM US/ Global Project Manager, SAP implementation, Responsible for education of user base. Developed and managed the team that designed, built and delivered education for the deployment of SAP

	in IBM, using early hybrid education model.
1984-1986	Australian Institute of Administration, University of N.S.W., Sydney, Australia
	Guest Lecturer
1984-85	IBM Australia
	Executive Education Manager
	Responsible for development and delivery of education programs for senior executives of IBM customers
	Conducted programs for Australian government, Senior Executive service
	Responsible for programs and events for senior customer executives in Singapore, Hong Kong, China, Thailand
1984	Macquarie Graduate School of Management, Macquarie University, Sydney, Australia
	Lecturer, "Managing with computers"
1980-1982	IBM Australia
	International executive conference manager
	Responsible for the development and planning of international industry conferences in Monte Carlo and Sydney
Other experience	
2011-	Clear Yoga, Rhinebeck, NY
	Yoga (Iyengar) and Meditation (Mindfulness) Instructor
2010-2012	The Good Dog Foundation
	Volunteer handler with my Australian Shepherd, Maggie for Autistic children at Andersen school
2009-	Rhinebeck Chamber Music Society
	Consultant to the board;
	On database marketing, patron administration.
2007 -	Retired from IBM
	Walden University, PhD Candidate, Counseling Psychology
1994-2007	IBM Corporation
	Customer Information Data Steward, 2005 to 2007
	Synergy Project Executive, Customer Relationship Management, 2004-2005
	Marketing Project Team Lead CRM, 2002-2004
	Project Executive, CRM Siebel Implementation and Global Siebel Consulting Competency Executive, 1999-2002
	Principle Consultant, IBM Global Services, SAP Practice, 1996-1999
	Project Manager, SAP implementation, 1994-1996
Highlights	Customer Information Data Steward:
	Refined IBM's existing worldwide customer database to foster more accurate data entry, to allow trend analysis to understand client needs and to improve promotional campaign hit rate. Worked with senior executive team in developing vision and approach to IBM's marketing databases.
	Built a consolidated worldwide view of the customer that improved understanding of global accounts and introduced consistency of data, allowing ongoing trend analysis for all levels of customers.

Led the project team to improve data hygiene and matching including the implementation of a new run once global engine to bring together customer data consistently across the world. Replaced multiple local and application specific matching engines creating consistency

Project Executive, CRM Siebel Implementation and Global Siebel Consulting Competency Executive:

Directed the project to consolidate more than 100+ legacy systems into three coordinated regional environments.

Education, Communications Executive for Siebel deployment

Led development of curricula, courses, materials, communications and messages to successfully deploy innovative program to more than 20,000 people worldwide

Consulting executive and lead for customer implementations, Principal Consultant, IBM Global Services, SAP Practice:

Led long-term implementations of critical customer databases for a Dutch medical supply company, a Swedish global gas company, and a Japanese global electronic company. Working with Board and senior management visioning and outcome definition through implementation with high levels of customer satisfaction

1972-1994 IBM Australia

Business Transformation Manager, Asia Pacific Fulfillment, 1991-1994

Opportunity Manager, Logistics, IBM Asia Pacific. 1990-1991

Executive Assistant General Manager, General Business Group, IBM Australia

1989 - 1990

Sales Manager, Sydney General Branch, IBM Australia 1986-1989

Executive Education Manager, Asia Pacific 1983- 1986

Business Planning Specialist, Melbourne 1983-1984

Sales Representative, Melbourne Industry Branch, Pharmaceutical and Distribution industry 1982-1983

Distribution Programs Manager and Manager International Industries Conferences, 1980-1982

Marketing Representative Manufacturing Industry 1978-1980

Systems Engineer, Sydney, GBG, 1976-1980

Data Centre Administration Lead 1974-1976

Call Centre, Office Products 1973-1974

Administrative Assistant, IBM Sydney Finance Branch, 1972-1973

Highlights Business transformation Manager(Asia Pacific Fulfillment)

Spent 4 years within IBM, in the re-engineering of IBM's logistics and fulfillment in Australia, and then in the Worldwide Fulfillment Organization

Opportunity Manager, Logistics (Asia Pacific)

Worked with organizations in the Manufacturing, Wholesale, Distribution and Service industries. Focused in Logistics, Change Management, Marketing, Strategic Planning and Information Technology in Logistics and CRM. Managed projects in Logistics, Distribution, Fulfillment, and Sales and Marketing and re-engineering those functions.

	Executive Education Manager IBM Australia (Asia Pacific): Led programs and facilitated work sessions with customer Board and senior management to educate in the integration of IT with business requirements and facilitate the use of data to improve business results.
1969-1970	J.R.Robbins, Footwear Manufacturers, Sydney Australia Cost Accountant
1968-1969	Australian Wool Testing Authority, Sydney, Australia Accounts Clerk
Awards	Consulting Top Achiever 1998 IBM 100% club- Sales Achievement award 1978-1980 Rookie of the year 1978
Areas of expertise	The psychology of organizations, strategic planning, process analysis and management, complex global project and program management, executive engagement, enterprise level implementations of SAP and Siebel, data management implications of large application enablement, systems integration of complex environments and migrations of legacy environments. Data enabled marketing Proven track record of leading disparate teams to take vision to reality through the implementation of process and application changes. Strong experience with the definition and management of data at an enterprise level for large multinational organizations Meta-analysis and database analysis.
Other interests	Grief –skills working with people who have had significant loss in their lives both individually and with groups. Neuropsychology in yoga and meditation- Use yoga and meditation as skills to help people live better, especially with chronic illness.
Professional organizations	Association for Death Education and Counseling Student initiative Chair (2008-2010) Volunteer Recruitment Committee Chair (2010-2013) American Psychological Association IYNAUS- Iyengar Yoga: National Association of the United States
Personal Information	Australian Citizen with US permanent residency. Australian private pilot's license with formation, aerobatics and tail dragger endorsements. Student of Yoga and eastern philosophy, Iyengar Introductory 1 teacher. Quilter, knitter and fabric artist. Speaker of English, with rudimentary Russian, French and Japanese.