

# Family Involvement in Adult Chronic Disease Care: Reviewing the Systematic Reviews

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## Abstract

Health care providers, policy makers, and investigators are dependent upon the quality and accuracy of published research findings to inform and guide future practice and research in their field. Systematic reviews, the synthesis of outcomes across studies are increasingly more common in the family literature; however, published review reports often lack information on strategies reviewers used to insure dependability of findings, and minimize methodological bias in the review. In this article, we summarize findings from systematic reviews of interventions and outcomes from family involvement in adult chronic disease care published between 2007 and 2016. In addition, we explore procedures reviewers used to insure the quality and methodologic rigor of the review. Our discussion provides guidance and direction for future studies of family involvement in chronic disease care.

## Keywords

family intervention, chronic illness, adults, systematic review

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Family involvement in the care of a community-based adult is widely recommended as superior to patient-only interventions (Campbell, 2003; Chesla, 2010; Lyons & Lee, 2018; Martire, Lustig, Schulz, Miller, & Helgeson, 2004; McDaniel, Hepworth, & Doherty, 2003; Rolland, 2018; Rosland & Piette, 2010). These recommendations are grounded in the assumption that family health and function influence the health status and functioning of individual family members; therefore, combining patient and family management interventions should produce better outcomes for both patient and family. Despite the assumption, the scientific evidence supporting this recommendation has been inconsistent in the literature. In this article, we present evidence from 10 systematic reviews of family involvement in adult chronic disease care, published from 2007 to 2016, and discuss whether and how the findings from those systematic reviews provide direction for future studies of family involvement in the chronic disease care of adults.

## **Background**

Our interest in analyzing the body of research data addressing family involvement in adult chronic disease management is long-standing. We have collected and evaluated the outcomes of family intervention research related to care for chronically ill adults since 1992 (Gilliss & Davis, 1992, 1993). Consistent with the conclusions of other family scientists at that time, our work indicated that family-focused care yielded nonsignificant or only marginally better outcomes. We attributed the weakly positive effects reported in family intervention research reports to such factors as (a) the preponderance of small study samples with insufficient power for hypothesis testing; (b) the scarcity of psychometrically sound, family-level data collection instruments; and (c) the lack of long-term follow-up studies to allow investigators to evaluate change over time. To date, there is limited consensus on whether or how family involvement in chronic disease care for family members is beneficial.

Chesla (2010) completed a review of meta-analyses of randomized clinical trials of family intervention research and narrative summaries to examine the evidence that family interventions improve health. The 5-year review period, 2004-2009, included published materials located through CINAHL, Medline, and PsycINFO; excluded those focusing on mental health, health promotion, and substance use interventions; and included reviews that focused on adults and children. She found “salutary effects of family interventions” for patient health and mental health and for family member health and reasonable evidence supporting family intervention for children with type 1 diabetes (Chesla, 2010, p. 355).

In this article, we present the findings from an overview of 10 systematic reviews of family involvement in adult chronic disease care, using Chesla's classification of family interventions as "psycho-educational interventions" (those directed at increasing skill and/or knowledge for managing the illness) or "relationship-focused interventions" (those directed at improving skills for family relationships while living with the demands of chronic illness, including conflict management, communication or problem-solving skills) (Chesla, 2010, p. 359).

The aim of our overview of these systematic reviews was to determine whether the literature reported stronger evidence for family intervention than was previously reported. In an effort to address the overall aim, we addressed two questions:

1. Which family interventions (psychoeducational or relationship-focused) are most often reported to improve chronic disease management outcomes for adults and their family care partners? We asked this question to explore the validity of different types of family intervention. In other words, were the interventions "family" focused?
2. Given that standards for reviewing systematic reviews continue to evolve, in what ways do reviewers control/minimize the risks of bias and maintain quality in their systematic reviews? We asked this question to evaluate the scientific rigor of the systematic review.

## Method

### *Eligible Systematic Reviews*

We elected to conduct this overview of systematic reviews of intervention studies that included family involvement in care for a chronically ill adult. We limited our search to English-language reviews published in the decade 2007 through 2016, to minimize changes in chronic disease care over time. We used recommendations from the *Cochrane Handbook for Systematic Reviews of Interventions* (Higgins & Green, 2011) and used *PICOS* categories (*Participants, Interventions, Comparisons, Outcomes, Study design*) in developing a form for reviewing the systematic reviews of published study reports of family-inclusions in chronic illness care for an adult family member.

### *Terms*

Given the contemporary variations of the definition of "family member," we elected to be broadly inclusive, including "family caregiver," "carer," or

“care partner” as the spouse, other relative, friend, neighbor, or significant other, involved in helping the chronically ill adult manage the chronic disease. Our approach parallels that used in most of the contemporary family literature we reviewed.

## Searches

We searched electronic databases PubMed, MEDLINE, CINAHL, PsycINFO, ERIC, SCOPUS, as well as the Cochrane Database of Systematic Reviews (Higgins & Green, 2011). We used recommendations from Moher and colleagues (2009) to formulate required categories for our overview of systematic reviews; from McKenzie et al (2013) to describe meta-analytic strategies used; and Guyatt et al (2011) for approaches to assess the risk for bias in each systematic review. The content recommended for systematic reviews is displayed in Table 1.

## Study Inclusion/Exclusion Criteria

Eligible reviews required the participation of the person with the illness and an adult care partner. We excluded reviews of family interventions for mental illness, head injuries, and/or cognitive diseases (i.e., dementias and Parkinson’s disease), as these illnesses often result in significant cognitive loss for the ill individual and complicate self-care collaboration. In addition, we omitted reports of studies in which interventions focused exclusively on the chronically ill adult *or* the care partner. A complete description of our search process and terms appears in the supplemental material (Supplement 1).

Our search of electronic databases resulted in 342 reports. Hand searching of reference lists from these reports yielded an additional 15 reviews for a total of 357. Using our study search form, two members of the review team independently classified the first 174 reviews reports. After further refinement of the form, two members of the review team classified all 357 reports, resolving disagreements through discussion or, in selected cases, through consultation with a third reviewer. The complete list of all 357 studies appears in the supplemental material (Supplement 2). We developed a PRISMA model (Figure 1) for illustrating review decisions to retain or exclude individual study reports, based on recommendations from Liberati and colleagues (2009).

Our search produced systematic reviews of two types: those focused on a single-disease and reviews that addressed multiple chronic diseases. The seven, single-disease reviews focused on the most common chronic diseases among adults (National Center for Chronic Disease Prevention and Health Promotion, 2016): diabetes ( $n = 1$ ), cardiovascular disease ( $n = 2$ ), and

**Table 1.** Commonly Recommended Content for a Systematic Review Report.**Review objective(s)**

Does the report include a clear purpose statement about the importance of a review for the science? Are the desired populations/samples defined? The intervention?

**Study eligibility**

Are study selection criteria identified a priori for literature searches?

**Search resources**

Are multiple databases(s) searched to identify eligible studies? Are additional sources cited and described (e.g., hand searches, reference lists)? Were two or more reviewers involved in making decisions about study selections? Is the process of making these decisions explained in the report?

**Characteristics of individual studies**

Does the description of individual studies include information about eligible study designs, sample characteristics, for example, number of participants/comparison/control groups? Subject attrition? Is comparison/control group “usual care” described?

**Interventions/outcomes**

Does the report contain descriptions that include information on independent (treatment) and dependent (key outcomes) variables, treatment delivery, and dosage about each study?

**Findings**

Are key outcomes described within and across studies presented and discussed? If meta-analyses are conducted, do they provide confidence intervals and measures of consistency for each analysis?

**Conclusions and recommendations**

Do conclusions evolve clearly and logically from the review findings? Do recommendations speak to the significance of findings for practice, research, and/or policy related to the science?

**Bias assessment**

Does the report include a discussion of strategies used to assess for risks of bias (i.e., in study selection, study reporting, data synthesis, analysis, identification of possible confounds) as well as the quality and the dependability of their outcomes?

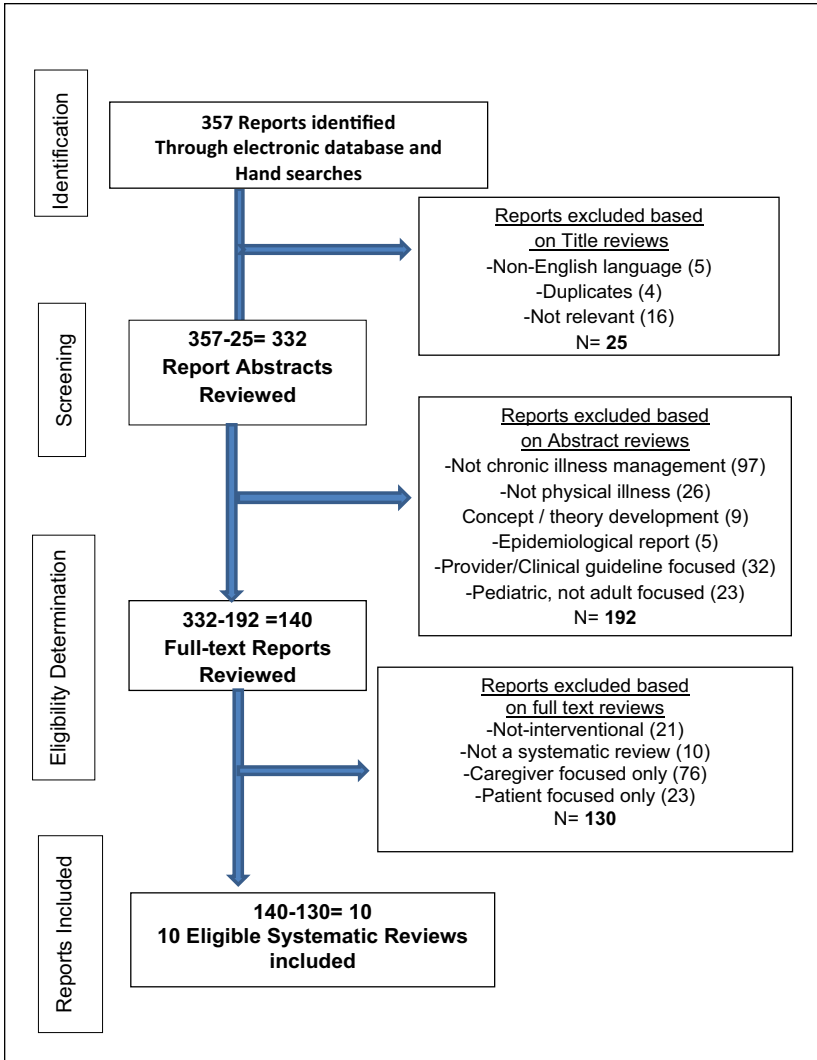
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Sources. Guyatt et al. (2011); McKenzie et al (2013); and Moher, Tetzlaff, Altman, Altman, and The PRISMA Group (2009).

cancer ( $n = 4$ ). The multiple disease reviews addressed two or more chronic diseases. Detailed descriptions of each systematic review appears in Table 2.

## Findings

The results of this analysis focused initially on the question of whether family intervention brings about a beneficial response and one that is superior to



**Figure 1.** PRISMA model for selecting eligible systematic reviews 2007-2016.

usual care focusing on the individual: Which family interventions (i.e., either psychoeducational or relationship-focused) are most often reported to improve chronic disease management outcomes for adults and their family care partners?

**Table 2.** Systematic Reviews of Family involvement in Adult Chronic Disease Care.

Diabetics	Citation	Review objective(s) Participant demographics	Intervention focus(es) Treatment dosage/delivery Comparison Group(s) contacts	Key Outcomes Findings/Conclusions Quality / Bias Assessment
Torenholt, Schwennesen, and Willaing (2014). <i>Diabetes Medicine</i> 1989-2012	<p><b>Objectives:</b> Synthesize published family intervention literature around adults with Type I/II diabetes and, determine whether interventions were family-centered.</p> <p><b>Participant Demographics:</b> Adults age 18 and older with Type I or Type II diabetes, plus and at least one family member</p> <p><b>Searches:</b> 4 studies focused on a single ethnic grp: Chilean, Native American, Mexican American, Native Hawaiian</p> <p><b>Sample:</b> No other demographic data reported.</p>	<p><b>Interventions:</b> All 10 studies addressed diabetic adults' disease knowledge &amp; management</p> <p>4 of 10 studies involved a family member in diabetic adult's goal setting, problem solving, diet and physical activity</p> <p><b>Dosage:</b> Intervention contacts: 3-16 contacts, over 3-12 months.</p> <p><b>Delivery methods:</b> 4 studies reported 'tailoring' interventions to address cultural differences</p> <p><b>Comparison/Control Group(s):</b> Not discussed in review.</p>	<p><b>Key Outcomes:</b> 9 of 10 studies focused on measuring the diabetic adult's disease knowledge, HgA1C level, psychosocial behaviors, and perceptions of family involvement</p> <p>2 of 10 studies included measures of family members blood sugar, diet and exercise behaviors</p> <p><b>Findings/Conclusions:</b> 8 of 10 studies did not include, or were missing family data in assessment batteries</p> <p>Family involvement across the 10 studies was "modest" at best, and future studies need stronger theoretical justification for involving families in diabetic care.</p> <p><b>Quality/ Bias Assessment</b> PRISMA modeling (Liberati et al, 2009) illustrated study inclusions/exclusions.</p>	
From 1480 studies; 10 met criteria, yielding 800 participants				

(continued)

Table 2. (continued)

Coronary Heart Disease (CHD)		Intervention focus(s)	Key Outcomes
Citation	Review objective(s)	Treatment dosage/delivery	Findings/Conclusions/
Study Designs/ Searches/Samples	Participant demographics	Comparison Group(s)	Quality / Bias Assessment
Reid, Ski, and Thompson (2013). <i>PLOS-ONE</i>	<b>Objectives:</b> Evaluate effectiveness of "psychological" interventions for patients with coronary heart disease and their partners.	<b>Interventions:</b> Pt and Partner: Psychosocial strategies focusing on disease counseling, enhancing social support and increasing quality of life	<b>Key Outcomes:</b> CHD patient risk factors, morbidity, mortality, depression, anxiety, quality of life
<b>Review period:</b> 1984-2002			Care Partner: depression, anxiety, quality of life
<b>Study Designs:</b> RCTs only	<b>Participant</b>		CHD patient and partner: knowledge of disease and treatment, social support, satisfaction with care
<b>Medline, EMBASE, CINHLA, PsycInfo, the International Clinical Trials Registry (for unpublished studies) and the Cochrane Register of Controlled Trials</b>	<b>Demographics:</b> Adults 18 and older with various cardiovascular diseases. Mean age = 50.9-62.9	<b>Dosage:</b> Varied 20-90 minute sessions in daily/weekly/monthly contacts	Findings/Conclusions: 3 of 7 studies measured both patient and partner responses
searched in October, 2012, using terms such as CHD, stress, depression, anxiety, couple group psychotherapy and marital therapy.	Partners: 18 and over who attended 50% or more treatment sessions	Intervention contacts varied across studies from 3-16 sessions over 3-12 months.	2 of the 7 studies showed 'modest' outcome improvements
<b>Sample</b>	No other demographic data reported.	<b>Delivery:</b> Face to face or phone contacts for group/individual counseling by various interventionists (nurses, psychologists, social workers, physicians)	<b>Quality/ Bias Assessment:</b> Two reviewers independently applied Cochrane Collaboration's tool (Higgins & Green, 2011) to explore for study selection bias.
1290 reports reviewed		Comparison/Control Group(s): "Usual care"	Meta-analyses (Higgins, Deeks & Altman (2008) were used to compare findings in studies with similar key outcome measures.
7 considered eligible			Reid et al, judged bias assessment strategies across the seven reports to be generally poor.
N= 673 participants			

(continued)



**Table 2. (continued)**

Cardiovascular/Stroke	Review objective(s) Participant demographics	Intervention focus(s) Treatment dosage/delivery Comparison Group(s) contacts	Key Outcomes Findings/Conclusions/ Quality / Bias Assessment
<p>Citation Vallury, Jones, and Gray (2016), <i>Topics in Stroke Rehabilitation</i>.</p> <p><b>Review period:</b> 1946 to 2014</p> <p><b>Study Designs:</b> controlled and non-controlled trials</p> <p><b>Searches:</b> Eight databases were searched, including (Medline, Embase, PsychINFO, Ovid, CINAHL, Web of Science, Scopus, the Cochrane Library, and hand searches for papers published prior to April 2014. Both controlled and non-controlled trials were eligible for inclusion in the review. Twenty-two of the 25 reports meeting selection criteria were RCTs.</p> <p><b>Sample:</b> 2732 citations: 25 considered eligible, 22 RCTs N=3739 stroke survivors <b>NB:</b>studies in which only carers reported depressive symptoms were considered ineligible.</p>	<p><b>Review Objective:</b> Identify family-oriented interventions that prevent/manage post-stroke depression in stroke pts &amp; their care partners</p> <p><b>Participants:</b> Stroke survivors and their family care partners</p> <p><b>Demographics:</b> No other demographics included</p>	<p><b>Interventions:</b> Stroke survivors and care partners received: Problem-solving, goal-setting &amp; "practical" skills training</p> <p>Referral to community services; and Counseling as needed.</p> <p><b>Dosage:</b> 12 weeks -12 months of contacts</p> <p><b>Delivery Methods:</b> Multi-component interventions were tailored to family needs, and delivered via face-to-face and/or phone contacts, by a "health professional"</p> <p><b>Comparison/Control Groups:</b> Not discussed in review</p>	<p><b>Key Outcomes:</b> Post-stroke survivor/ family care partner depressive symptoms (pre-stroke depressive symptoms not reported)</p> <p><b>Findings/Conclusions:</b> 4 of the 25 studies showed few post-stroke depressive symptoms for stroke survivors</p> <p>1 of 25 studies showed few symptoms for both carer and survivor</p> <p>Studies with the fewest depressive symptoms post-stroke were those with tailored multi-component interventions, delivered immediately after hospital discharge, and continued for over time.</p>
<p><b>Quality/Bias Assessment:</b> Reviewers used Moher's 27-item checklist to guide study selection (Moher et al, 2009), and PRISMA modeling to illustrate study inclusion/exclusion decisions (Liberati et al, 2009). The RCTs were evaluated with Cochrane bias assessment criteria (Higgins &amp; Green, 2011). GRADE scales (Guyatt et al, 2011) were used to evaluate non-RCT studies. Eleven reports were judged low risk for bias; 12 as "some" or "high" risk of bias; and, two were judged sufficiently "unclear" to make a judgment.</p>	<p>(continued)</p>		

Table 2. (continued)

Citation	Review objective(s) Participant demographics	Intervention (s) Treatment dosage/delivery Comparison Group(s) contacts	Key Outcomes Findings/Conclusions Quality / Bias Assessment
Griffin, Meis, et al (2014) <i>Journal of General Internal Medicine.</i>	<b>Objectives:</b> Explore: (1) whether family interventions improve cancer patient outcomes; (2) benefits of one intervention over another.	<b>Interventions:</b> Cancer Patient: Telephone or web-based counseling, symptom mgmt. Couples: Cognitive-behavioral therapy, support/counseling. Care Partner: cancer symptom recognition/management training Other unique interventions <b>Dosages:</b> Varied across studies <b>Comparison/Control Groups:</b> usual care; wait list; active control; individualized; and other	<b>Key Outcomes:</b> Patient quality of life (physical, psychological & social); symptom control; health care utilization; depression/anxiety; and relationship adjustment <b>Findings/Conclusions:</b> Assessment batteries focused primarily on patient outcomes 13 of the 18 trials showed no significant differences between family-involved and usual care Patient-only treatment was equally effective as family-focused treatment Reviewers concluded variability in study populations and interventions prevented pooling data across studies in a meaningful way.
<b>Review period:</b> 1996-2012 <b>Study Designs:</b> RCTs only <b>Searches:</b> <i>Indices of Medicine, (Ovid) and PsycINFO 1996-December 2012.</i>	<b>Participant Demographics:</b> Patients with cancers, including prostate, breast or solid tumor type Adult cancer patients, 18 or older, along with individuals (related or not), who provided direct care and support to the patient. Pts were 80% married; 51% male; 21% non-white Care partners were 61% female		
<b>Sample:</b> 2,771 cancer trial reports reviewed; 18 eligible trials.			

(continued)

**Table 2. (continued)**

Cancer	Review objective(s) Participant demographics	Intervention (s) Treatment dosage/delivery Comparison Group(s) contacts	Key Outcomes Findings/Conclusions Quality / Bias Assessment
Citation Review period Study Designs/ Searches/Sample			<p><b>Quality/ Bias Assessment:</b> Reviewers used the <i>Cochrane Collaboration Criteria</i> (Higgins, Altman et al., 2011) for estimating risk of for bias. <i>Low risk</i> studies were classified as <i>Good Quality</i> if investigators, data collectors, and study participants were blind to subject treatment group assignment; intent-to-treat analyses was conducted, and participant withdrawals and dropouts were followed-up for each group. <i>Fair Quality</i> (moderate risk for bias) studies were those in which blinding was unclear, intention to treat analyses was omitted, or withdrawal/ drop-out subjects were not discussed for individual groups. <i>Poor Quality</i> (high risk for bias) classifications assigned when blinding was not clarified or missing, and/ or intention-to treat analysis and/or withdrawal/drop-outs were missing from the study report. <i>Agency for Healthcare Research and Quality criteria</i> (Owens et al., 2010) for evaluating strength of evidence for each outcome (<i>high, moderate, low, and insufficient</i>) on the basis of whether further research was deemed likely to change estimate of effects. While study effect sizes were not reported, Griffin and colleagues judged 15 of the 27 trials to be only "Fair" Quality (moderate risk for bias); and the strength of evidence for family versus individual intervention outcomes to be "low" for all outcomes.</p>

(continued)

Table 2. (continued)

Cancer	Review objective(s) Participant demographics	Intervention (s) Treatment dosage/delivery Comparison Group(s) contacts	Key Outcomes Findings/Conclusions Quality / Bias Assessment
Hopkinson, Brown, Okamoto and Addington-Hall (2012). <i>Journal of Pain &amp; Symptom Mgmt.</i>	<b>Objectives:</b> Explore effects of psychosocial interventions on cancer patients & their family carers <b>Participants Demographics:</b> Patients with cancer and their care partner "Family Carer" was defined as someone who gives care (could be unrelated) Professional caregivers not eligible Participants age (Mean=58 yrs) Study attrition rates: none to 88% (Median=38%)	<b>Interventions:</b> Varied combinations of disease education; problem-solving skill-training; and counseling delivered in couple-focused contacts.  Couples given "homework" assignments <b>Dosage:</b> 20-80 minutes sessions over 2-24 weeks <b>Delivery:</b> Interventions delivered in face-face sessions with couple, and/or via telephone contacts; audio video tapes; computer program delivery; home visits; written materials Interventionists included nurses, social workers, and psychologists <b>Comparison/Control Groups:</b> Contacts not described	<b>Key outcomes:</b> Couple reports of disease symptom management Quality of life (physical, psychological, & social, carer support for helping patient with problems) Pt support for helping carer manage problems <b>Findings/Conclusions:</b> Disease management was major intervention focus across studies; All studies focused on one family member carer; 7 of 22 studies included aspects of couple communication around relationship support; Couple-oriented relationship support interventions were most likely to improve the emotional health of both patient & family carer <b>Quality/ Bias Assessment:</b> Hopkinson and colleagues used Cochrane search criteria to select studies (Higgins & Green, 2011), and PRISMA modeling (Liberati et al, 2009) to illustrate inclusion/exclusion decisions.
<b>Review period:</b> 1998-2010			
<b>Study Designs:</b> Experimental only			
<b>Searches:</b> <i>Medline, EMBASE, PsycInfo/NFO, and CINAHL, were used searched, using MeSH terms cancer, family, career, interventions, therapy, symptom, problem and quality of life</i>			
<b>Sample:</b> 1951 reports reviewed; 22 considered eligible N=3493 couples; between 14-480 couples randomized to groups			

(continued)

**Table 2. (continued)**

Cancer	Review objective(s) Participant demographics	Intervention (s) Treatment dosage/delivery Comparison Group(s) contacts	Key Outcomes Findings/Conclusions Quality / Bias Assessment
<p>Li and Loke (2014). <i>Psychology Oncology</i></p> <p><b>Review period:</b> Up to 2013</p> <p><b>Study designs:</b> 12 RCT &amp; 5 cohort studies</p> <p><b>Searches:</b> English or Chinese-language from the initiation dates of the following four databases publications up to March 2013 were included: PsychINFO (1806), Medline (1950), Science Citation Index Expanded (1970), and OVIDSP/CINAHL (1982)</p> <p>study reports using the terms: <i>intervention, program, cancer, oncology, carcinoma, therapy, AND couple, partner, spouse, carer, and caregiving.</i></p> <p><b>Sample:</b> 410 reports reviewed: 17 eligible; studies included between 9 and 263 couples.</p>	<p><b>Objectives:</b> Explore existing interventions, contents and approaches, and outcomes for spousal couples coping with cancer, and identify directions for future interventions</p> <p>Couple attrition 6-34%</p> <p>Mean=20%</p> <p><b>Participant Demographics:</b> Patients with cancer and their care partner</p> <p>No other demographics included</p>	<p><b>Interventions:</b> Dyadic coping, appraisal and adjustment; Care skills training (11 studies); Therapeutic counselling (6 studies); Psycho-education (2 studies); and Combination of care skill training and psychoeducation (11 studies). Delivery Methods: Face-to-face couple encounters at clinic visits, via group sessions, home visits or telephone contacts Interventionists included psychologists, therapists, nurses, counselors, and social workers who used standardized intervention protocols.</p> <p><b>Dosages:</b> Between 1 and 16 weeks of couple sessions (Mean was 6.2 weeks) of 20 -79 minutes encounters. Follow-up varied between 8 weeks and 12 months</p> <p><b>Comparison/Control Group:</b> Not described in report</p>	<p><b>Key outcomes:</b> Pt situational appraisal, coping and adjustment, mental and physical health; Partner situational appraisal, coping and adjustment, mental and physical health; and Dyadic situational appraisal, problem-solving coping and adjustment, marital satisfaction.</p> <p><b>Findings/Conclusions:</b> Couples who participated in skill training reported: (1) less illness uncertainty (3 studies); (2) better communication (4 studies); (3) more positive coping (2 studies); and (4) greater marital satisfaction (6 studies).</p> <p><b>Quality/ Bias Assessment:</b> The <i>Effective Public Health Practice Project Criteria:</i> EPHPP (Thomas, Ciliska, Dobbins, &amp; Micucci, 2004) were used to classify selection bias, study design, confounds, blinding, data collection methods, and study participant attrition rates. Based on EPHPP findings, four studies ranked “Strong”, and 13 ranked “Moderate” due to low participant retention and high attrition across studies.</p>

(continued)

**Table 2. (continued)**

Cancer	Citation	Review objective(s) Participant demographics	Intervention (s) Treatment dosage/delivery Comparison Group(s) contacts	Key Outcomes Findings/Conclusions Quality / Bias Assessment
	Regan, Lambert et al. (2012). <i>BMC Cancer</i> .			
	<b>Review period:</b> 1990-2010			
	<b>Designs:</b> Experimental & Quasi-experimental studies			
	<b>Searches:</b> CINAL, PSYCHO, EMBASE, and ISI Web of Science were searched using terms: <i>couple or partner, caregiver, family, spouse, husbands, wives, close relatives, next of kin, significant others, relative, AND cancer or neoplasm</i> . In addition, individual investigators in the filed were contacted about similar under review or in-press.			
	<b>Sample:</b> 709 reports reviewed; 23 eligible; 17 met all criteria. Total sample included 3285 (1678 patients & 1607 partners) providing complete data.			
		<p><b>Objectives:</b> Identify couple-based interventions for patients with cancer and their partner; Explore efficacy of these interventions; Explore intervention content delivery; and Identify key elements of interventions that promote adjustment to cancer diagnosis.</p> <p><b>Participant Demographics:</b> Patients with cancer on their care partner Participants across all studies were 80% Caucasian, well educated, mid-fifties. "Couples" were adult cancer patient &amp; spouse, partner or other family member. Attrition rates across studies: 26% patients; 29% partners.</p>	<p><b>Interventions:</b> Disease management (e.g., symptom recognition &amp; treatment); Stress &amp; coping skills (e.g., relaxation techniques); Dyadic communication (e.g., "coaching")</p> <p><b>Delivery Methods:</b> Face-to-face or phone contacts by professional interventionists with varied backgrounds and (psychologist, social workers, nurses)</p> <p><b>Dosage:</b> Varied: 6 contact hours to a 4-day seminar</p> <p><b>Comparison/Control Group(s):</b> Usual care; Attention control; and Wait-list</p>	<p><b>Key Outcomes:</b> Pt / Partners' depressive symptoms, anxiety, perceived quality of life</p> <p><b>Findings/Conclusions:</b> Couple-based interventions for cancer-related psychological and social difficulties were as effective as Patient-only or partner-only interventions; only 2 of 17 studies showed couple interventions superior to Patient-only or partner-only intervention.</p> <p><b>Quality/Bias Assessment:</b> Reviewers used PRISMA modeling (Liberati, et al. 2009) to illustrate inclusion/exclusion decisions, and National Health and Medical Research Council guidelines (1999) to assess levels of evidence and bias minimization strategies in the 23 studies. Studies judged on selection bias in study design, blinding, data collection methods, confounders, withdrawals/drop-out numbers. Eight studies ranked "Strong." The remaining 15 studies ranked "Moderate" due to high attrition rates.</p>

(continued)

**Table 2. (continued)**

Multiple Chronic Diseases	Citation Review period Study Designs/ Searches/Sample	Review objective(s) Participant demographics	Types of intervention (s) Delivery method (s) Comparison Group(s) contacts	Key Outcomes Findings/Conclusions Quality / Bias Assessment
Hartmann, Bazner, Wild, Eisler, and Herzog (2010), <i>Psychotherapy and Psychosomatics</i>	<b>Objective:</b> Use meta-analyses to assess the effects of family-oriented interventions on adults with chronic physical diseases	<b>Intervention(s):</b> Psychoeducational and/or Relationship-oriented	<b>Key outcomes:</b> Patient physical & mental health	
<b>Review period:</b> 1982-2007	<b>Participant Demographics:</b> Adult patients, age 18 or older, with a chronic physical disease: CVD (27 studies); Cancer (15 studies); Arthritis (5 studies); Diabetes (2 studies); AIDS (2 studies); and Lupus (1 study).	<b>Methods:</b> Trial intervention delivery methods not discussed	<b>Findings:</b> Meta-analytic results indicated family-oriented interventions were more effective than standard care for:	
<b>Study Designs:</b> RCTs only	<b>Dosage:</b> Contacts lasted between 30 minutes and 7.5 hours (Median =6.25 hrs)	<b>Comparison/Control Groups:</b> "Standard medical care" was the most common comparator group	(1) patient physical health (Hedges $g=0.32$ ); (2) patient mental health (Hedges $g=0.28$ ); and (3) family carer health (Hedges $g=0.35$ ). The reported odds ratio [1.72-1.84] indicated that family involvement had a 72-84% better chance of improving patient outcomes.	
<b>Searches:</b> Register of Controlled Trials and the Cochrane Database of Systematic Reviews (Issue II), plus MEDLINE, PsycINFO and CINAH were conducted using MeSH terms chronic diseases, family information, information/education/intervention/ psychotherapy and randomized controlled trials	Family carers, including spouses, other relatives, friends, and neighbors with close relationship to patient. 52% of carers were women; ages 29-79 (Mean=53)	<b>Quality/ Bias Assessment</b> Hartmann and colleagues assessed methodological quality of reports with regard to randomization, allocation concealment, follow-up of those who did not continue in the study and intention-to-treat analysis. They noted inconsistencies in methodological quality across the trials; sensitivity analyses indicated study quality differences did not significantly influence their statistical findings.		
<b>Sample:</b> Of 261 reports: 52 eligible, including 8,896 patients.	Professional caregivers were ineligible to participate			

(continued)

Table 2. (continued)

Multiple Chronic Diseases	Review objective(s) Participant demographics	Types of intervention (s) Delivery method (s) Comparison Group(s) contacts	Key Outcomes Findings/Conclusions Quality / Bias Assessment
<p>Citation Martire, Schulz, Helgeson, Small, and Saghafl (2010). <i>Annals of Behavioral Medicine</i>. 1990-2011 <b>Review period:</b> <b>Study Designs:</b> RCTs <b>Searches:</b> MEDLINE and PsycINFO databases for published reports of couple interventions in randomized trials of adult chronic disease management; MeSH terms physical diseases, therapeutics, and dyads were used <b>Study Sample:</b> 50 RCTs; 33 eligible for review; 25 met criteria for meta-analysis.</p>	<p><b>Objective:</b> Present a cross-disease review of the characteristics and findings of studies evaluating couple-oriented interventions for chronic physical illness <b>Participants/Demographics:</b> Characteristics of individual study participants not described. Reviewed studies included: CVD (6 studies); Prostate cancer (5 studies); Breast cancer (4 studies); Mixed cancers (4 studies); Osteo-arthritis (4 studies); Chronic pain (4 studies); HIV (2 studies); and Type II diabetes (1 study).</p>	<p><b>Interventions:</b> Patient received Cognitive-behavior skill training; Coping skills training; Exercise therapy; and Stress management. The couple received communication skills training; and symptom and pain management training. <b>Delivery Methods:</b> Face-to-face; telephone contact; and group sessions for couples. <b>Dosage:</b> Between 3 and 20 sessions; Follow-up varied between immediate post-treatment up to 12 months.</p>	<p><b>Key outcomes:</b> Patient depressive symptoms; patient pain; and marital functioning. <b>Findings/Conclusions (Meta-analysis):</b> Couple-oriented intervention was superior to patient-only intervention outcomes for the following outcomes: (1) Patient Depressive symptoms (<math>d=0.19</math>, <math>CI=0.00-0.37</math>); (2) Patient Pain (<math>d=0.18</math>, <math>CI=0.00-0.35</math>); and (3) Marital functioning (<math>d=0.16</math>, <math>CI=0.00-0.32</math>). Couple-oriented intervention was superior to usual care outcomes for the following outcomes: (1) Patient Depressive symptoms (<math>d=0.15</math>, <math>CI=0.02-0.27</math>); (2) Patient Pain (<math>d=0.20</math>, <math>CI=0.05-0.34</math>); and (3) Marital functioning (<math>d=0.17</math>, <math>CI=0.03-0.31</math>) <math>I^2 p \leq .05</math></p>
		<p><b>Comparison/Control Groups:</b> Attention-control; "usual medical care"; and wait-list.</p>	<p><b>Quality/ Bias Assessment</b> <b>Quality/ Bias Assessment</b> Martire and colleagues weighted each <math>d</math> statistic (before aggregation) to ensure larger sample studies would contribute a proportionally greater amount to the overall effect size of the studies. They reported both fixed and random effects meta-analyses yielded similar outcomes.</p>

(continued)



**Table 2. (continued)**

Multiple Chronic Diseases	Citation Review period Study Designs/ Participant Searches/Sample	Review objective(s) Participant demographics	Types of intervention (s) Delivery method (s) Comparison Group(s) contacts	Key Outcomes Findings/Conclusions Quality / Bias Assessment
Deek, Hamilton et al. (2016). <i>Journal of Advanced Nursing</i> . <b>Review period:</b> 2000-2014	<b>Objective:</b> Explore whether family- involved interventions improve outcomes of adults living with chronic conditions. <b>Participants/Demographics:</b> Patients with chronic varied diseases, including: obstructive pulmonary disease; vascular disease; hip fracture; stroke; cancers, HIV; and medical or surgical back conditions. "Family caregiver" was defined as the person the patient identified as the primary source of support, who provides physical or emotional care. No other demographics reported.	<b>Interventions:</b> Educational sessions in hospital or home with patients and family caregivers on disease self-care and coping skills; Caregiver disease education and management support; Transition from hospital to home 'coaching' for caregivers. <b>Delivery Methods:</b> Variable numbers and duration of contacts by way of: in-hospital contacts; home visits after transition; home phone contacts with patient and/or caregiver <b>Comparison/Control Groups:</b> "Usual care"; and "control" group (but treatments were not described)	<b>Key Outcomes:</b> Patients: Medication adherence; hospital readmission; perceived quality of life; satisfaction with care; and costs of hospitalization. <b>Findings/Conclusions:</b> Results varied across disease groups: Improved self-care behaviors among heart failure adults; improved medication adherence in HIV pts; Improved quality of life for stroke pts; Reduction in number of ED visits and hospital re-admission rates for various chronic conditions groups. Coping skills training intervention were most likely to result in stable change.	
<b>Searches:</b> Medline (Ovid), CINAHL, Academic Search Psycholinfo and Scopus. English language databases were searched for the period 2000-2014, using search terms <i>family, spouse, carer, caregiver, chronic, chronic disease, self-care, self-management, and self-efficacy</i> .	<b>Study Sample:</b> 1270 reports identified: 10 met eligibility criteria	<b>Quality/ Bias Assessment</b> Deek et al used both the Cochrane Risk Assessment criteria (Higgins, Altman et al. 2011) and the Cochrane Collaboration Effective Practice and Organization of Care (EPOC) Guidelines (Higgins, Deeks, & Altman, 2008) to guide sample selection and minimize sampling bias. They used the GRADE system (Guyatt et al, 2011) to assess certainty of evidence in the ten studies, concluding only "moderate" certainty, and study information judged to be "unclear" for risk of bias.		

## **Interventions**

Although categorizing the interventions proved to be difficult from the data included in the review papers, the majority of family interventions included psychoeducational interventions focusing on skill building and knowledge for disease management. When relationship-focused interventions were implemented, they were effective (e.g., “family” counseling; Griffin et al., 2014; Reid, Ski, & Thompson, 2013; Vallury, Jones, & Gray, 2016) but many reports noted the absence of two partners in the intervention. Most reports evaluated outcomes that targeted at the affective state or quality of life or the patient and/or the family member, rather than a measure of the family relations or functioning. Theoretical justification for the intervention designs was largely absent and, as might be expected, the family relationship outcomes were inconsistently measured.

As shown in Table 2, definitions of “family” varied widely across the 10 reviews, including related and nonrelated persons (Griffin et al., 2014), spouses (Li & Loke, 2014), and friends and neighbors (Torenholt, Schwennesen, & Willaing, 2014). In some cases (Martire, Schulz, Helgeson, Small, & Saghafi, 2010; Torenholt et al., 2014; Vallury et al., 2016), the intervention programs addressed the well-being or depressive symptoms of the spouse/partner.

Linking the effectiveness of specific interventions to results was not possible, given the limited information provided in the reviews. As shown in the details of Table 2, the majority of reports show effectiveness in changing the behavior or health status of the patient and some show weak improvements in spouse/partner depressive symptoms. Depressive symptoms and marital satisfaction outcomes were most often reported as improved when the intervention was delivered to the family dyad and targeted shared coping skills.

Practically speaking, the content of the described interventions suggested that the “family member” was often included as a surrogate for the health care provider and the health care system. Family members were used as substitutes for professionals to deliver needed care, monitor, or encourage the patient to obtain goals. These psychoeducational approaches contrasted with the interventions intended to strengthen the family’s ability to work effectively together in the present or in future challenging situations. Overall, the interventions included in the reviews were limited in theoretical underpinnings, and specifically lacked detail on the expected mechanism that would produce change.

We wonder whether the field would benefit from moving toward the use of Realist Evaluation (Manicas & Secord, 1983) in its evaluation of social changes such as family intervention. Such approaches acknowledge the complexity of social change and the difficulty of measuring cause and effect outcomes.

Given the state of the intervention research with families, we propose that a more effective framework for the study of change in families include (a) a more detailed examination of the *context* in which the change is proposed (i.e., which disease and with what distinctive features and with which “family member” as the care partner), (b) a clearer description of the *mechanism* for change (i.e., what is expected to change and why do we believe the intervention would affect this change), and (c) a focus on the *outcome* (i.e., what do we expect would change?) that could be measured and linked to the mechanism. The reported reviews, generally, lacked a coherent connection to viewing the interventions and outcomes in relation to one another.

Question 2 focused on whether and how the reviewers of the 10 systematic reviews assessed the quality of the review: Given that standards for reviewing systematic reviews continue to vary, in what ways do reviewers control/minimize the risks of bias and maintain scientific rigor in their systematic reviews?

### *Review Quality/Bias*

Guidance for initiating systematic reviews (i.e., selecting a topic, formulating research questions, developing search criteria, and conducting literature searches) are readily available. However, there is less direction for evaluating the quality of findings and methodological rigor of the review and, as Pollock, Fernandes, Becker, Featherstone, and Hartling (2016) have pointed out, existing guidelines can be confusing and often are contradictory. As shown in Table 2, a variety of approaches were used to assess bias and quality in these 10 systematic reviews including: the Cochrane Bias Assessment Tool (Higgins, Altman et al., 2011), the Cochrane Effective Practice and Organization of Care (EPOC; Higgins, Deeks, & Altman, 2008), GRADE (Guyatt et al., 2011), the Australian National Health and Medical Research Council (NHMRC; 1999) guidelines the Agency for Health care Research and Quality ranking criteria (Owens et al., 2010), and the Effective Public Health Practice Criteria (Thomas, Ciliska, Dobbins, & Micucci, 2004) for reviewing literature. Overall, assessing the bias and rigor of these reports was a challenge.

### **Discussion**

The proliferation of systematic reviews on families and chronic illness in adults has justified the need for “umbrella” reviews that synthesize findings across systematic reviews and enable investigators to identify patterns as well as discrepancies in findings. Such high-level oversight, combined with critical details, holds the promise of identifying directions for future research.

Our intent for this “umbrella” review was to compile findings from multiple systematic reviews to answer questions about the effectiveness of “family intervention” and to evaluate the quality and rigor of those reviews. Unfortunately, our findings may discourage those who would promote the health of the family and the well-being of the adult members with chronic illness by way of “family” interventions.

The heterogeneity of diseases, samples, treatment content, dosage, delivery methods, and outcome measures complicate meaningful data synthesis across these family studies. Most of the conclusions and recommendations addressed by the reviewers proposed further research, in contrast to implications for practice or policy.

The studies included in the review appear to feature problems that have long plagued family scientists, including how to recruit and retain family members into clinical trials. Studies rely on the inclusion of “family members,” as defined by the person with the illness. As such, the samples include lifelong spouses/partners, as well as children and neighbors willing to help. Study outcomes may be attenuated by the mixture of relationships that intermingle enduring intimate relationships with the concrete aid of neighbors offering social support. Four of the 10 systematic reviewers cited recruitment and retention problems in their discussion of findings in the studies reviewed. It is also possible there is a mismatch between the expectations of families at the time they enroll in intervention studies and the burden of participation, at a time when the burden of care is high, and the questions raised by uncertain benefit outweigh the value of participation. The well-being of the “family” may seem less relevant at a time when family members are focused on the needs of the patient. Findings from this overview indicate exploring for and controlling bias in a systematic review continues to be challenging for experienced as well as neophyte investigators in the field of family science.

Existing guidelines for evaluating systematic reviews in health care specialties (e.g., medicine, pharmacology and various physical therapies) continue to evolve over time as the result of seeking input from clinicians, investigators, policy makers, and other stakeholders often through consultation with experts in other fields, for example, bio-engineering and economics. As shown in Table 2, the outcomes of these endeavors have resulted in guidelines with quality and bias judgment on issues ranging from *consistency* and *precision* (GRADE) to *blinding on outcomes assessment* (Cochrane Collaboration), and *Strong*, *Weak*, or *Moderate* for NHMRC scores (see <https://www.nhmrc.gov.au/about-us/publiatoins/how-review-evidence>).

Although these are important issues, it is difficult, if not often impossible, to equate quality and methodological rigor judgments across studies when different review guidelines are used. Based on our “umbrella” review of the

10 systematic reviews on family involvement in adult chronic disease care, we propose it may be time for family scientists to consider developing supplemental or unique guidelines that include methods for evaluating the quality and rigor of family intervention outcomes (e.g., context, resources) to be used for evaluating family science reviews.

## Conclusion

Although more systematic reviews of family intervention have been published in recent years, the evidence for the *added value of family intervention over intervention with a single individual* has generally not demonstrated added value for the family. In contrast, the majority of these studies do show some benefit to the identified patient. In all likelihood, this stems from a common approach to interventions in which family members or other informal care partners are employed as surrogates for formal health care providers. In these interventions, the family members are included as effectors seeking a change in the patient's behavior/outcomes. When the coping ability or partnership between family members is the focus of the intervention, the results are more likely to demonstrate reductions in depressive symptoms for the patient and/or family members and, in some cases, for the longer term coping of the family/couple. In other words, when family change is truly the target of the intervention and family behavior or a proxy for satisfaction with family life measured as an outcome, the research results are more likely to demonstrate a positive value for the family.

The available approaches to the evaluation of the quality and bias of reviews of family interventions vary considerably and, arguably, are not well suited to studies of family intervention. We conclude that family research would benefit from the development of quality/bias frameworks that are particular to studies of family intervention and address some of the major concerns we and others have identified. These concerns include confirmation that family was the target of intervention, identification of the mechanism for expected change, confirmation that a dimension of family was measured as a key outcome, consistency in sampling approaches and inclusion criteria, and replicable descriptions of the intervention, its timing, and its intensity. Finally, given the concerns of nursing—as a practice discipline—we encourage the development of conclusions for family practice including greater focus on understanding the contexts in which interventions can be seen to make a difference.

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