Breast Cancer: Targets and Therapy

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REVIEW

# Coping Assessment Tools in the Family Caregivers of Patients with Breast Cancer: A Systematic Review

This article was published in the following Dove Press journal:
*Breast Cancer: Targets and Therapy*

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**Background:** Breast cancer is a problem that affects not only the individual's health and quality of life, but also the functionality of the family system. Caregivers experience stress when their patients cannot cope with the symptoms of their disease. The stress experienced by caregivers gives rise to psychological and physical symptoms in them. This study seeks to present a complete set of tools for assessing coping in the spouses or caregivers of women with breast cancer and evaluate the various instruments developed within these lines of inquiry.

**Methods:** A search was carried out in PubMed, Scopus, Web of Science, CINAHL, PsycINFO, Medline, ProQuest, Scopus and Google Scholar and also in the reference lists of the key articles retrieved for any coping assessment instrument targeting family caregivers' needs that had acceptable psychometric properties and was published until September 2019. The instruments used to assess coping in the spouses and caregivers of women with breast cancer were thus identified and their properties were described.

**Results:** Overall, 88 adaptation assessment tools related to family caregivers of patients with breast cancer were identified in 28 related articles. The tools examine different dimensions of adaptation such as satisfaction, stress, burden and needs of spouses and caregivers of patients with breast cancer.

**Conclusion:** Assessing family caregivers' coping is essential for providing them with the appropriate sources of support. Although several instruments have been used to assess coping in the spouses and caregivers of women with breast cancer, the properties of these instruments have to be examined before they can be more widely implemented.

**Keywords:** coping, assessment tools, caregivers, breast cancer, family

## Introduction

Breast cancer is the most common cancer among women in both developed and developing countries. The incidence of breast cancer is increasing in the developing world due to the increase in life expectancy and urbanization and the adoption of western lifestyles.[1,2] Breast cancer affects 2.1 million women each year and is responsible for the greatest number of cancer-related deaths among women. In 2018, an estimated 627,000 women died of breast cancer, comprising approximately 15% of all cancer-related deaths among women. While breast cancer rates are higher among women in more developed regions, the rates are increasing globally in nearly every region.[3]

Breast cancer is a problem that affects not only the patients' mental and physical integrity, but also their family caregivers' health. Caregivers experience stress symptoms, such as depression, anxiety, fear, loneliness, psychosomatic symptoms

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DovePress
http://doi.org/10.2147/BCTT.S240928

and marital problems, and physical symptoms, such as fatigue, anorexia, indigestion, constipation, serious sleeping disorders and pain.[4] Among the caregivers of breast cancer patients, spouses are usually the primary caregivers who take on more caregiving responsibilities than other family members; therefore, the spouses of breast cancer patients are subject to unique challenges that are different from those experienced by other family caregivers. For example, the commitment and obligations that form part of any marriage may heighten people's assessment of their caregiving responsibilities. Some aspects of adaptation are also only applicable to spousal relationships (eg, sexual adaptation, household management and concerns about the children's and family's future).

Adaptation to breast cancer is not merely a personal issue of the patients, but it also directly affects the spouse and family members of the patient. Throughout the process of adaptation to breast cancer, patients and their caregivers need to manage cancer-related problems and distress as well as make arrangements in different life domains.[5]

Several reviews have been conducted on the caregivers of cancer survivors. For example, Goldswig et al found that the caregivers of cancer patients have a low social support and are not adequately capable of adapting to this enormous pressure.[6] Li et al wrote in a review article that the wives of cancer patients have negative experiences of providing care to their patients, and this experience has adverse effects on the whole family.[7] The wide spectrum of problems experienced by cancer patients mandates their examination from different aspects in the view of the spouses and caregivers of these patients. The problems experienced by caregivers are very similar in different societies, but there may be slight variations based on the culture and conditions governing each society, which require further scrutiny.[8,9] For example, in Islamic and Arab countries, religious strategies are more widely used to adapt the patients and their caregivers to the disease.[10]

The caregivers of breast cancer patients tend to report reduced physical functioning, lower vitality, reduced immunity, increased physical symptoms and sleep problems. Compared to husbands with healthy wives, the husbands of breast cancer patients reported a significantly lower level of vitality and physical quality of life.[10,11] Mortimer et al[12] found that men who had lived longer with a spouse's breast cancer showed a greater suppression of their cutaneous delayed-type hypersensitivity response.[13]

Breast cancer patients' treatment and disease status can affect the husband's or caregiver's physical well-being. Compared to the husbands of healthy women, husbands with a wife undergoing chemotherapy and mastectomy reported more physical symptoms and lower physical quality of life.[11] These findings suggest that the husbands' physical well-being is also likely to deteriorate when their wife is being treated for a disease, and coping is crucial in these situations.

In the process of coping with cancer, caregivers need to manage their emotional distress and solve specific cancer-related problems (eg, treatment difficulties and reallocation of household tasks). Nurses should provide appropriate care to patients and their caregivers in order to assess their adaptation. Investigating adaptation to the disease among male caregivers can be helpful both for the men themselves and ultimately their wife with breast cancer. Specialized tools are needed to measure coping in the spouses of women with breast cancer. Given the clinical impact as well as the economic consequences of breast cancer on caregivers, knowing the overall experiences of caregivers in supporting and caring for patients can be very helpful. An important component of addressing this issue is the selection of the most appropriate tool for measuring the[14] impact of breast cancer on caregivers.[14] This systematic review was therefore carried out to identify any instruments used for assessing informal caregiving in breast cancer and describe their measurement properties in this population. Such information will guide clinicians in addressing the aspects of caregiving most in need of support in this group.

The objectives of this review include:

The first purpose of this systematic review to identify the instruments used to assess coping in spouse and family caregiver in breast cancer patients and describe their measurement properties if assessed in this population. Second, the various instruments developed within these lines of inquiry will be critically evaluated.

# Methods

## Search Strategy

Relevant literature was identified through a systematic electronic database search of Medline, CINAHL, PsychINFO, ProQuest, PUBMED, Scopus, Web of Science and Google Scholar since 1966–2019 using the keywords "Adaptation, Psychologic or Psychologic Adaptation or Psychological Adaptation or Coping Behavior or Behavior, Coping or Behaviors, Coping or Coping Behaviors or Coping Skills or Coping Skill or

Skill, Coping or Skills, Coping or Behavior, Adaptive or Adaptive Behavior or Adaptive Behaviors or Behaviors, Adaptive" AND "Caregiver or Carers or Carer or Care Givers or Care Giver or Spouse Caregivers or Caregiver, Spouse or Caregivers, Spouse or Spouse Caregiver or Family Caregivers or Caregiver, Family or Caregivers, Family or Family Caregiver" AND "Breast Neoplasm or Breast Tumor or Breast Cancer" AND "Instrument or Tools or Scale or Questionnaire or Psychometric." The search was limited to articles published in English. The reference list of each relevant study was searched for additional papers.

## Eligibility Criteria

This systematic review was reported according to Preferred Reporting Items for Systematic Reviews and Meta-Analyses[15] guidelines.[15] Eligible studies had to state in the objectives, methods or rationale that they were focused on coping assessment tools in the family caregivers of patients with breast cancer and include a self-administered assessment instrument. Instruments could be used to evaluate the negative (e.g., burden), positive (eg, satisfaction) or both aspects of caregiving, e.g., caregiver burden/distress, psychological status and mood or health-related quality of life. All original quantitative studies applying, testing or developing an instrument were eligible (e.g., cross-sectional, cohort, nonrandomized/randomized controlled trials, case studies). Studies with a mixed-methods design and interventional studies were included if quantitative data were available. Searches were restricted to studies published in English. Qualitative studies, magazines, news, electronic resources and reports, abstracts, were excluded, although their references were searched for relevant articles. Studies that lack the tools needed to address caregivers and insufficient information to evaluate in the original article were excluded.

## Selection of Articles

Two reviewers (MJSN and FSH) independently performed the initial screening of the articles based on their type of publication and relevance to the scope of the review according to their title and abstract. Then, the full text of each potentially relevant article was screened to decide its eligibility. The level of inter-rater agreement was calculated using Cohen's Kappa statistic, considering the following cut-off points:[16] Slight agreement (≤0.20), fair agreement (0.21–0.40), moderate agreement (0.41–0.60), substantial agreement (0.61–0.80) and almost perfect agreement (≥0.81).

## Data Extraction and Synthesis

One researcher extracted data from the included studies and the other authors checked for the accuracy and completeness of the data. Data extraction was performed using a pre-developed and standardized form to guarantee the consistency of the extracted data with regard to:

1. Instrument characteristics: Name and abbreviation, original reference, life domain/construct, number of items, rating system and score range (total scale and/or subscale scores). When information was lacking, the original reference was searched;
2. Country and study population in which the measurement properties of the instrument were assessed.
3. Identification of the measurement properties of the instruments used to assess the caregivers of patients with breast cancer. According to the Consensus-based Standards for the Selection of Health Measurement Instruments[17] checklist, the following measurement properties could be identified: 3.1. Validity through content validity, construct validity (ie, hypothesis testing, structural validity and cross-cultural validity), and criterion validity (ie, concurrent validity, predictive validity); 3.2. Reliability through internal consistency, reliability, measurement error; 3.3. Responsiveness through definitions of the measurement properties is described elsewhere.[17]

## Methodological Quality of the Studies

The COSMIN checklist (http://www.cosmin.nl/) was used to evaluate the quality of the studies assessing the measurement properties of the instruments. The checklist includes nine boxes with standards for different measurement properties based on a 4-point rating scale ("excellent," "good," "fair" and "poor") and a set of criteria.[18] The quality of the studies was assessed independently by two reviewers (MJSN and FSH). In case of disagreement, a third reviewer was consulted. This procedure was also carried out to assess the quality of the measurement properties of the instruments. Finally, the general strengths and weaknesses of each instrument were assessed and included as summary tables.

# Results

## Study Selection

The literature search yielded a total of 2609 records. After the duplicates were removed, 983 records were screened through their title and abstract. After reviewing the abstracts, 143 articles were intensively reviewed. Subsequently, 28 articles were investigated. Based on the inclusion criteria, Eighty-eight coping tools were identified (Figure 1).

The exclusion criteria consisted of not using an instrument for assessing family caregivers and spouses or providing no information about the instrument, having a qualitative design or being irrelevant. Overall, 28 articles were included, all of which were published in English. Most articles were published after the year 2000 (26 articles), and ten of them (28 articles) were published over the last 5 years (ie, 2014–2019). The studies were conducted in America (n = 17), Europe (n = 5), Asia (n = 3) or Oceania (n = 2). The inter-rater agreement regarding study selection was significant (Kappa >0.76). Disagreements were resolved by consensus.

The results generally show that a variety of studies have used a range of tools to measure adjustment in spouses and caregivers of breast cancer patients, and there is no specific tool to assess adaptation in family caregivers of breast cancer patients, and in some cases compatibility tools have been used that are not relevant to this topic.

## Instruments

Table 1 presents the list of accessed instruments and their characteristics based on their life domain/construct. Sixty-nine tools had been used in the various retrieved studies to assess coping dimensions in the caregivers of patients with breast cancer. None of the instruments were designed specifically for the caregivers of patients with breast cancer. Therefore, the researchers used a variety of instruments to measure coping in the families of patients with breast cancer. The tools included the Profile of Mood States, the Coping Responses Inventory, Snyder's Screening for Marital and Relationship Discord and the COPE Scale; distress was measured by the Brief Symptom Inventory (BSI) and everyday functioning using the Psychosocial Adjustment (PSA) questionnaire; other tools included the Satisfaction With Life Scale, the Locke–Wallace Marital Adjustment Test, measures of burden, the Quality of Life Questionnaire-C30 (QLQ-C30), the Duke Health Profile, the Ways of Coping Checklist (WCC), depression was assessed using the Center for Epidemiologic Studies Depression Scale (CES-D), coping using the Ways of Coping Questionnaire, Social support using the Interpersonal Support Evaluation List, Symptom Check List – Revised (SCL 90-R), Psychological Adjustment to Illness Scale (PAIS), Quality of Life Spouses Scale (QOL-SP), Illness Intrusiveness Rating Scale (IIRS), Dyadic Coping Dyadic Coping Scale (DCS), Emotional wellbeing was measured. Quality of Life Spouses Scale (QOL-SP), Illness intrusiveness was measured with the Illness Intrusiveness Rating Scale (IIRS), Mutuality Mutual Psychological Development Questionnaire (MPDQ), Sense of Coherence Scale, Spirituality Perspective Scale (SPS), Religious Coping Scale (RCOPE), The Health Index, the Impact of Event Scale, the Brief Index of Sexual Functioning.

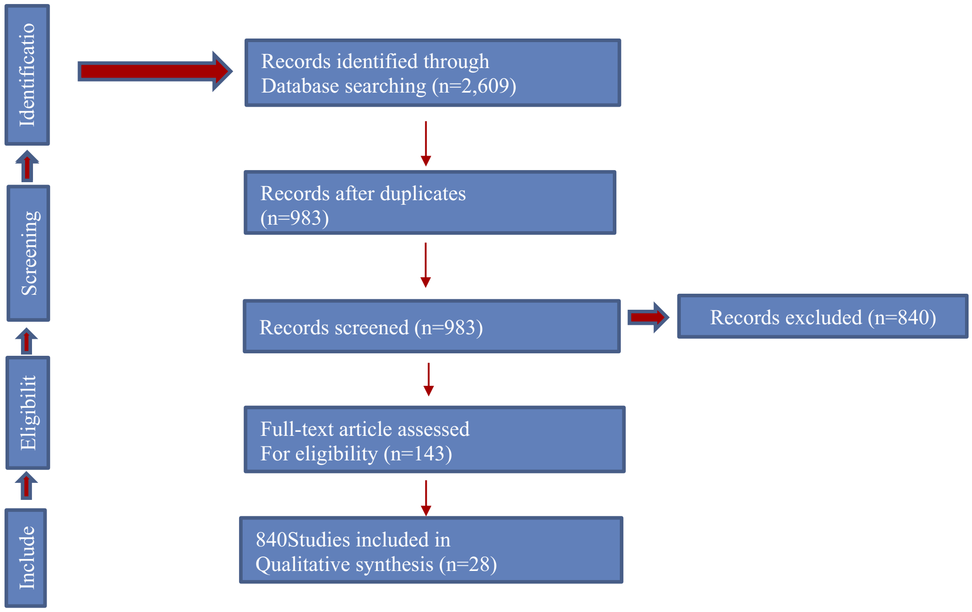

**Figure 1** PRISMA flow diagram.

**Table 1** Caregiver Coping Instruments

| Reference | Year | Country | Scale Name | Initial Test Population | Items/Format | Reliability |
|---|---|---|---|---|---|---|
| Megan L. Robbins[19] | 2019 | USA | COPE | 52 patients, and 51 spouses | Subscale consists of 4 items (Rated on a scale from 1 to 4,) | 0.63–0.68 |
| Karen Kayser & Chiara Acquati[20] | 2019 | USA | Dyadic Coping Scale | 86 Breast cancer patients 86 Partners | 61 items contains five subscales: Stress Communication, Common, Positive, Hostile and Avoidance of Dyadic Coping. (Likert scale ranging from "Never" 1 to "Always" 6 | 0.68–0.95 |
| William T. Dalton[21] | 2008 | USA | 1- The Profile of Mood States | 71 patients, and 71 spouses | 1-65-item instrument has 6 subscales(Likert scale) | 0.94–0.97 |
| | | | 2-The Coping responses Inventory | | 2-48-item measure is comprised of 8 scales((Likert scale) | 0.63 |
| | | | 3-The Snyder Marital Disharmony Scale | | 3-This scale consists of 18 items assessing overt marital discord, perceived difficulty with problem solving, and disagreements regarding finances as well as parental and spouse roles | 0.84 |
| | | | 4-The Sickness Impact Profile | | 4-This 136-item measure provides statements about health-related functioning in 12 domain | Physical subscale was 0.83, and the Psychosocial subscale was 0.88 |
| Robbins, Megan L[22] | 2012 | USA | Electronically Activated Recorder | Fifty-six breast cancer patients And their spouses | the external microphone | |
| | | | 2- adjustment questionnaires | | 1-Psychological adjustment (Center for Epidemiologic Studies<br>2-Depression Scale (CES-D, Radloff, 1977), a 20-item)<br>3-Relationship adjustment. The Dyadic Adjustment Scale (DAS; Spanier &Thompson, 1982, a32-item scale with four subscales: consensus, tension, cohesion, and overall dyadic adjustment)<br>4-Physical Health. The 36-item Short Form (SF-36; Ware, et al, 1993). With four subscales, physical ability, energy, pain, and general health | (CES-D)=0.86–0.92<br>(DAS)= 0.92–0.89<br>(SF-36)= 0.94 |

(*Continued*)

**Table 1** (Continued).

| Reference | Year | Country | Scale Name | Initial Test Population | Items/Format | Reliability |
|---|---|---|---|---|---|---|
| Hasida Ben-Zur[23] | 2001 | Israel | Self-coping using the COPE scale | Seventy-three breast cancer patients and their spouses | *1-A* 30-item short Hebrew version of the COPE scale coping<br>2-problem-focused[10] scale<br>3-The perceived other-coping emotion-focused[24] scale | PF scale=patients being (alpha=0.73), and for spouses (alpha=0.82)<br>EF scale patients (alpha = 0.79), and for spouses (alpha = 0.69) |
| | | | Distress was measured by the Brief Symptom Inventory (BSI) | | 4-The Brief Symptom Inventory (BSI). The BSI is a shortened version of the SCL-90-R with 53items and nine dimensions (likert) | BSI = 0.48-0.80 |
| | | | Everyday functioning was assessed by the Psychosocial Adjustment (PSA) questionnaire | | 5-the Global Severity Index (GSI) | GSI score patients (alpha = 0.97), and for spouses (alpha=0.96). |
| | | | | | 6-Psychosocial Adjustment (PSA) a 15-item scale measuring functioning in five domains(likert) | Patients (alpha =0.78), and for spouses (alphas.74). |
| Silvia M. Bigatti[25] | 2011 | USA | 1-Copingvways of coping questionnaire | Husbands of women with breast cancer[26] and without breast cancer[12] | 1-Coping ways of coping questionnaire (66 items. Items are grouped into 8 subscales-four of which make up the problem focused coping scale and 4 make up the emotion-focused) | $\alpha$ = 0.83 for emotion-focused coping and $\alpha$ = 0.84 for problem focused coping. |
| | | | 2- Center for Epidemiological Studies Depression Scale(CES-D) | | 2-CES-D= 20-item(likert) | $\alpha$ = 0.89 |
| | | | 3- the Subjective Stress Scale | | 3-subjective stress scale= 4-item(likert) | $\alpha$= 0.83 |
| | | | 4- the Satisfaction With Life Scale | | 4-satisfaction with life scale 5-item(likert) | $\alpha$ = 0.88 |
| | | | 5- the Locke-Wallace Marital Adjustment Test | | 5-marital satisfactionvlocke-wallace marital adjustment test=15 items | $\alpha$ = 0.70 |
| | | | | | 6-Burden=<br>1-Activities of Daily LivingVIllness Impact Form(ADLs)<br>2-Role Strains-Psychological Adjustment to Illness Scale 46-item includes 7 domains | 1-ADLs $\alpha$= 0.81<br>2- $\alpha$ = 0.54 |
| | | | 6- Measures of burden. | | | |

(*Continued*)

**Table 1** (Continued).

| Reference | Year | Country | Scale Name | Initial Test Population | Items/Format | Reliability |
|---|---|---|---|---|---|---|
| Silvia M. Bigatti[27] | 2011 | USA | 1-Depression—Center for Epidemiologic Studies Depression Scale (CES-D) | Husbands of women with breast cancer[24] and without chronic illness[22] | 1-(CES-D) This 20-item self-report instrument | CES_D,$\alpha$=0.90 |
| | | | 2-Coping—Ways of Coping Questionnaire Coping strategies | | 2-67items | $\alpha$=0.61 to $\alpha$=0.79 |
| | | | 3-Social support—Interpersonal Support Evaluation List | | 3-40-item | $\alpha$=90 |
| Bonnaud-Antignac, Angélique[28] | 2012 | France | 1-Quality of Life Questionnaire-C30 (QLQ-C30) | 100 patients and their caregivers | 1-30 items | |
| | | | 2- Duke Health Profile and Ways of Coping Checklist(WCC) | | 1-DHP includes 17 items<br>2-WCC contains 27 items include 3 domain | (1) emotion-centered coping (9items, alpha coefficient of 0.72)<br>(2) problem-centered coping (10 items, alpha coefficient of 0.79)<br>(3) social support-centered coping (8 items, alpha coefficient of 0.73). |
| Ross E. Carter[29] | 1993 | USA | Individual adjustment.<br>1-Symptom Check List - Revised (SCL 90-R) | 14 couples | 1-SCL 90-R is a 90-item | 0.78–0.90 |
| | | | 2- Psychological Adjustment to Illness Scale (PAIS) | | 2-PAIS is a 46-item | 0.20–0.93 |
| | | | Marital adjustment.<br>1- the Dyadic Adjustment Scale<br>2-the Family Adaptability and Cohesion Evaluation Scale - 111 (FACES III)<br>3- the Clinical Rating Scale (CRS). | | Marital adjustment<br>1-DAS is a 32-item scale<br>2-FACES 111 contains 20 Likert-scale items | 1-DAS=0.42 to 0.90<br>FACES 111=0.84 |

(*Continued*)

**Table 1** (Continued).

| Reference | Year | Country | Scale Name | Initial Test Population | Items/Format | Reliability |
|---|---|---|---|---|---|---|
| Barry Feldman[30] | 2005 | England | 1-Emotional wellbeing was measured. Quality of Life Spouses Scale (QOL-SP) | 71males | 1-QOL-SP=13-item | 0.92 |
| | | | 2-Illness intrusiveness was measured with the Illness Intrusiveness Rating Scale (IIRS) | | 2-IIRS=13-item | 0.88 |
| | | | 3-Mutuality Mutual Psychological Development Questionnaire (MPDQ) | | 3-22-item | 0.90 |
| | | | 4-Dyadic Coping Dyadic Coping Scale (DCS) | | 4-61-item | 0.63 |
| Barry N. Feldman[31] | 2006 | England | 1-Quality of Life Spouses Scale (QOL-SP) | 71 male | 1-QOL-SP consists of 13 items | 0.92 |
| | | | 2-Illness Intrusiveness Rating Scale (IIRS) | | 2-IIRS consists of 12 item | 0.88 |
| | | | 3- Dyadic Coping Dyadic Coping Scale (DCS) | | 3-61-item | 0.63 |
| Jennifer harkness Hodgson[32] | 2003 | USA | 1-the Beck Depression Inventory (BDI) | 20 patients and 22 non-breast cancer patients, | 1- …. | 0.88 |
| | | | 2-The Dyadic Adjustment Scale | | 2- … | 0.85 |
| | | | 3-Short-Form Health Survey | | 3-36-item | 0.86 |
| Alexander Karan[33] | 2017 | USA | Electronically Activated Recorder | 52 couples | | 0.80–0.98 |
| | | | Dyadic Adjustment Scale | | DAS=32 items with likert scale | |
| Trace Kershaw[34] | 2004 | USA | COPE scale | 200 women and 200 of their family caregivers | 60-item | 0.63–0.81 for patients 0.71–0.79 for family caregivers |
| | | | Quality of life[12] | | 36 items | 0.72 for patients and 0.71 for family caregivers |
| Sedigheh Khanjari[9] | 2012 | Persian | 1-Persian version of Caregiver Quality of Life Index-Cance | 150 family caregivers | 1-consists of 35 items | 0.89 |
| | | | 2- Sense of Coherence Scale | | 2-consists of 13-item | T1 and T2 were 0.81 and 0.79 |
| | | | 3-Spirituality Perspective Scale(SPS) | | 3-consists of 10-item | 0.82 at T1 and 0.84 at T2 |
| | | | 4-Religious Coping Scale (RCOPE) | | 4-consists of 14 items | 0.82 and 0.80 at T1 and T2 |
| | | | 5-The Health Index | | 5-HI consists of 9 items | 0.77 at T1 and 0.79 at T2 |

(*Continued*)

**Table 1** (Continued).

| Reference | Year | Country | Scale Name | Initial Test Population | Items/Format | Reliability |
|---|---|---|---|---|---|---|
| Sharon Manne[24] | 2014 | USA | 1-Partner unsupportive behaviors | 330 patients and their spouses | 1-consisted of 13 items | 0.91 for both patient and spouse |
| | | | 2-Holding back sharing concerns. (adapted from Pistrang and Barker) | | 2-A 6-item scale | Patients 0.84, for spouses 0.81. |
| | | | 3- Mental disengagement subscale of the COPE was used (Carver et al, 1993) | | 3- | 0.61 for both patient and spouse |
| | | | 4- Behavioral disengagement | | 4-item scale | 0.60 for both patient and spouse |
| | | | 5-Global well-being. | | 5-14-item | 0.95 for patients and 0.94 for spouses |
| | | | 6-Cancer distress. Intmsions subscale of the IES (Horowitz, Wilner, & Alvarez, 1979) | | 6-14-item | 0.91 for both patient and spouse |
| Suzanne Nikoletti[35] | 2003 | Australia | Family Inventory of Needs–Primary Caregivers (FIN–PC) | 141 primary family caregivers | 30-item | 0.94 |
| | | | MBSS, which is designed to identify the informational coping style of respondents (Miller, 1987; Miller & Mangan, 1983) | | | 0.76 and 0.79 |
| Laurel l. Northouse[36] | 1995 | USA | Social Support Questionnaire (SSQ) | 81patients and 74spouses | 34-item | 0.87 for patients and 0.86 for husbands |
| | | | Uncertainty, Mishel Uncertainty in Illness Scale (MUIS) for patients and the Uncertainty in Illness Scale for family members (PCUS) | | 31-item | MUIS=0.90<br>PCUS=0.89 |
| | | | Symptom Distress Scale (SDS) | | 13-item | 0.84 for patients and 0.85 for spouses |
| | | | Beck Hopelessness Scale | | 20-item | 0.85 for patients and 0.83 for husbands |
| | | | The Brief Symptom Inventory(BSI) | | 53-item in nine subscales | 0.93 for patients and 0.94 for husbands |
| | | | The Psychosocial Adjustment to Illness Scale (PALS) | | 46-item | 0.90 for patients and 0.90 for husbands |

(*Continued*)

**Table 1** (Continued).

| Reference | Year | Country | Scale Name | Initial Test Population | Items/Format | Reliability |
|---|---|---|---|---|---|---|
| Amy K. Otto[37] | 2015 | USA | Daily capitalization and social support attempts(Patients and spouses completed daily diaries each evening that included lists of negative and positive events) | 99 couples | With 12 items assessed Positive and Negative Affect Form (PANAS-X; Watson & Clark, 1994) | 0.76 and 0.72 for patient and spouse NA 0.80 and 0.81 for patient and spouse PA |
| | | | the Dyadic Adjustment Scale | | | |
| Nelson Chun YiuYeung[38] | 2015 | China | 1-Caregiver guilt | 176husbands | 1-2-item scale with Likert scale | 0.84 |
| | | | 2-Caregiver Reaction assessment Scale (CRA) (Nijboer, Triemstra, Tempelaar, Sanderman, & van den Bos, 1999) | | 2-Likert scale | 0.86 |
| | | | 3-Couple Satisfaction Index (CSI) (Funk & Rogge, 2007) | | 3-4-item | 0.94 |
| | | | 4-Cancer Perceived Agents of Social Support (CPASS) (Goldzweig et al, 2010) | | 4-2-item with Likert scale<br>5-9-item scale | 0.91<br>0.85 |
| | | | 5- participants' protective buffering behaviours (Suls, Green, Rose, Lounsbury, & Gordon, 1997) | | 6-Likert scale | 0.72 |
| | | | 6-Brief COPE (Carver, 1997) | | | |
| | | | 7- Conformity to Masculine Norms Inventory-46 (CMNI-46) (Parent & Moradi, 2009 | | 7-2-item with Likert scale | 0.84 |
| | | | 8-General health status subscale[12] (Ware, Kosinski, & Dewey, 2003) | | 8-36-item | 0.80 |
| Megan L. Robbins[39] | 2012 | USA | 1-Family Environment Scale((FES) | 127 spouses and families | 1-FES=9 items | 0.69 |
| | | | 2-Dyadic Adjustment Scale | | 2-DAS is a 32-item | 0.94 |
| | | | 3- and patient Profile of Mood States(POMS) | | 3-POMS=15items | 0.95 |
| Megan L. Robbins[40] | 2014 | USA | EAR device | 56 couples | | |
| | | | Psychological adjustment(CES-D, Radloff, 1977) | | 20-item | |
| Megan L. Robbins[41] | 2018 | USA | Electronically Activated Recorder | Fifty-two couples | | |
| | | | Center for Epidemiologic Studies Depression Scale (CES-D) | | 20-item | |

(*Continued*)

**Table 1** (Continued).

| Reference | Year | Country | Scale Name | Initial Test Population | Items/Format | Reliability |
|---|---|---|---|---|---|---|
| Rottmann Nina[42] | 2015 | Denmark | 1-Dyadic coping was assessed using the Dyadic Coping Inventory (Bodenmann, 2008). | 538 couples | 1-37-item | 0.69–0.85 |
| | | | 2- The Center for Epidemiologic Studies-Depression Scale (Radloff, 1977) | | 2-20 items | 0.90 |
| | | | 3- the Relationship Ladder (Kuijer, Buunk, De Jong, Ybema, &Sanderman, 2004) | | 3-Self-anchoring Scale(0–10) | |
| Karine Baumstarck[43] | 2017 | French | 1-French version of the Brief COPE | 398 Patient and caregiver | Includes 28 items | 0.7 |
| | | | 2-quality of life[12] using the French version of the | | | |
| | | | Short form health survey questionnaire | | SF36 contains 36 items describing 8 dimensions | |
| Jennifer L. Scott[44] | 2004 | Australia | Couple communication (using videotapes) Coping, psychological distress, sexual functioning, and body image | 94 women and their partners | 2-WOC–CA, 44-item | 0.87–0.96 |
| | | | 2-Coping Questionnaire—Cancer Version(WOC–CA) | | 3-Psychological Distress subscale (seven items) the Sexual Difficulties subscale (six items) | 0.87–0.95<br>0.81–0.86 |
| | | | 3-Psychosocial Adjustment to Illness Scale—Self Report (PAIS–SR; L. P. Derogatis, 1986) | | | |
| | | | 4-the Impact of Event Scale (IES; Horowitz, Wimer, & Alvarez, 1979) | | 4-15 items | 0.80–0.91 |
| | | | 5-The Sexual Self Schema Scale (SSS) for Women (Andersen & Cyranowski,1994) | | 5-50-items | 0.78–0.82 |
| | | | 6-the Brief Index of Sexual Functioning (BISF; Leiblum & Rosen, 2000) | | 6-30-items | 0.62-0.95 |
| | | | 7-Client satisfaction questionnaire (CSQ) | | 7-13 items | 0.85 |

(*Continued*)

**Table 1** (Continued).

| Reference | Year | Country | Scale Name | Initial Test Population | Items/Format | Reliability |
|---|---|---|---|---|---|---|
| Northouse, Laurel L[45] | 1998 | USA | 1-Smilkstein Stress Scale (Smilkstein and Zimlich, 1990) | 131 couples | 1-18-item | 0.70 to 0.79 for patients and husbands |
| | | | 2-Dyadic Adjustment Scale, | | 2-32-item | From.92 to.95 for patients and husbands |
| | | | 3-Family APGAR(Smilkstein, 1978) | | 3-5-item | 0.86–0.92 |
| | | | 4-Social Support Questionnaire(SSQ) | | 4- 24-item with Likert scale | 0.86–0.94 |
| | | | 5- Mishel Uncertainty in Illness Scale(Mishel, 1981) | | 5-13-item | 0.79–0.86 |
| | | | 6- Beck Hopelessness Scale(Beck et al, 1974) | | 6-20-item | 0.80–0.85 |
| | | | 7-Brief Symptom Inventory (Derogatis and Melisaratos, 1983) | | 7- 53-item | 0.95–0.96 |
| | | | 8-Psychosocial Adjustment to Illness Scale (Morrow et al, 1978) | | 8-46-item | 0.81–0.94 |
| Hasida Ben-Zur[26] | 2001 | Israel | 1-COPE scale. | 73 patients with breast cancer and their spouses | 1- A 30-item short Hebrew version of the COPE scale | |
| | | | 2-Distress was measured by the Brief Symptom inventory (BSI) | | 2- The BSI is a shortened version of the SCL-90-R with 53 items | 0.48–0.80 |
| | | | 3- Global Severity Index (GSI) | | 3-GSI | Patients 0.97, and for spouses 0.96 |
| | | | 4- everyday functioning was assessed by the Psychosocial Adjustment (PSA) questionnaire. | | 4- 56-item questionnaire | Patients 0.78 and for spouses 0.74 |

## Measuring the Properties of the Instruments

Studies have used a variety of tools to measure coping in spouses and caregivers of patients with breast cancer, indicating the absence of a single and specific tool for measuring this and in some studies has been used to evaluate the compatibility of different tools in one study. All the studies offered a complete description of the sample population's characteristics and the country in which the instruments were applied as well as the methodological quality and quality of the measurement properties of the instruments. Internal consistency scores were reported for most of the instruments used and no information was given on criterion validity, structural validity, agreement or responsiveness. The inter-rater agreement was significant for the quality of the studies and the measurement properties of the instruments (Kappa>0.76).

## Methodological Quality of the Studies

Only one of the studies mentioned the validity of the instruments used to measure couples' satisfaction.[19] Studies testing the hypothesis of the instruments were classified as "fair"[7,9,19–34] or "poor".[7,35–45] Their common weaknesses included the failure to formulate hypotheses, describe the missing items or use a control measuring another construct. All the studies assessing internal consistency measured the tools' Cronbach's alpha.

## Discussion

Twenty-eight were studied, and in 22 studies, the priority of the target population was with the spouses of women with breast cancer. In each of these studies, different tools and several tools have been used to assess adaptation in spouses and family caregivers of patients with breast cancer. An important and remarkable issue in this study was the lack of specific tools for assessing coping in spouses and family caregivers of patients with breast cancer, which makes it difficult to conduct a detailed study and research.

The caregiving and spouse experience is a complex phenomenon that affects all the aspects of life. While the number of items in each domain differed in the different instruments, the instruments had many items in common. Since most of the questionnaires underwent some type of statistical testing to remove the non-statistically significant items, these domains appear to be critical for assessing the caregiving experience. Also, the experience of men living with a wife with breast cancer and cancer patient caregivers is very different and affects all the aspects of their life. Therefore, these instruments must be sensitive to the changes in the caregiver's and patient's status over time. Many of the instruments covered in this review had not adequately addressed this issue. The benefits of the existing tools include the innovative use of non-specialized tools for assessing the compatibility and shortage of these tools, and of course this lack of gauging of all aspects of adaptability has led researchers to achieve their research goal using several unrelated tools in the research.

Despite the 30 years of research about coping in the caregivers of breast cancer patients, we still know little about whether administering a caregiver questionnaire by itself in clinical settings has an impact on the caregiver or the patient.

Studying the available tools showed that they were not specifically designed for the family caregivers/husbands of patients with breast cancer and measured only one of the issues and needs of these individuals; meanwhile, the spouses of breast cancer patients have multi-dimensional problems. The next issue was the cultural incompatibility of the tools and their categories, which many scholars have admitted could endanger the credibility of the questionnaire. Health status is affected by social, educational, occupational, cultural and environmental conditions and these conditions should not be ignored.[46] The cultural and social factors affect the attitudes and expectations of the family members; moreover, the care conditions for different patients cannot be equally interpreted or measured by the same tool. The concept of compatibility should, therefore, be investigated in different environments and cultures and standard tools should be developed based on this concept.

Another important point is that most of the existing questionnaires were not based on a qualitative study, while qualitative studies can offer rich data, new insights and the lived experiences of individuals in a natural setting and consequently reveal the hidden angles of the concepts in question. Another major constraint mentioned was the translation of the tools. With literal or word-for-word translations, semantic differences in the combination of words and phrases or interpretations from a viewpoint due to different cultural norms are inevitable. The cultural validity and applied value of such tools are therefore low. A secondary approach is thus proposed, and new tools should be designed precisely based on empirical data and in compatibility with the social contexts studied. All structures and structures[47] are extracted accurately and precisely. Then, the questionnaires are formulated_ENREF_48.[48]

In addition to the changes in the health care marketplace, another truth is that, nowadays, more family members and friends are caring for chronically ill patients at home.[49–52] A challenge commonly experienced by all health care professionals is to keep in mind that these caregivers are also potential patients who need and deserve attention and care. The message is that care teams and health care professionals need to care for both the patients and their caregivers. Time and financial constraints already stretch most health professionals to the limit, which is why modifying clinical assessment tools and conducting studies about caregiver interventions are critical, because they help professionals learn when and how to intervene and assist the overly burdened caregivers of their patients.

This area of research is in need of more focused work, and most of the instruments examined in this review were limited by the fact that they had different patient populations.

Since the patient's spouse has been introduced as the best source of caregiving for cancer patients, their experiences can be used to build a suitable tool for monitoring patient compliance. The review of literature showed that, in spite of the high prevalence of cancer, there are no suitable tools for assessing coping in the spouses of patients with breast cancer. The design and construction of a suitable tool for achieving the said goal are therefore crucial. Nurses can help examine and recognize the needs of patients. Such tool must be specific to the spouses of patients with breast cancer and its items must be extracted based on the experiences of the patients' spouses and the social and cultural factors specific to these patients and their family. With the design of such tool, one can hope that effective measures will be taken to help reconcile breast cancer patients' spouses and the treatment team.

## Conclusion

The results of this review suggest that there is not a single specific tool for assessing coping in the spouses and caregivers of patients with breast cancer, and the use of diverse tools for this purpose may reduce the accuracy of research, and using non-specialized tools will also fail to address the specific issues experienced by this group of caregivers. Therefore, further research needs to be conducted on the design of tools to assess coping in this group of caregivers.

## Abbreviations

PRISMA, Reviews and Meta-Analyses; COSMIN, Consensus-based Standards for the Selection of Health Measurement Instruments; BSI, Brief Symptom Inventory; PSA, Psychosocial questionnaire; QLQ-C30, Quality of Life Questionnaire-C30; WCC, Ways of Coping Checklist; CES-D, Center for Epidemiologic Studies Depression Scale; SCL 90-R, Symptom Check List – Revised; PAIS, Psychological Adjustment to Illness Scale; QOL-SP, Quality of Life Spouses Scale; IIRS, Illness Intrusiveness Rating Scale; DCS, Dyadic Coping Dyadic Coping Scale; QOL-SP, Quality of Life Spouses Scale; MPDQ, Mutuality Mutual Psychological Development Questionnaire; SOC, Sense of Coherence Scale; SPS, Spirituality Perspective Scale; RCOPE, Religious Coping Scale.

## Data Sharing Statement

All data generated for this study are included in the article.

## Acknowledgments

This article results from a PhD thesis supported by Hamadan University of Medical Sciences. The authors gratefully acknowledge the financial support provided by vice chancellor of research and technology of Hamadan University of Medical Sciences.

## Author Contributions

All authors contributed to data analysis, drafting and revising the article, gave final approval of the version to be published, and agree to be accountable for all aspects of the work.

## Funding

This work was supported by Hamadan University of Medical Sciences, Hamadan, Iran No. 96030214356.

## Disclosure

The authors declare that they have no competing interests.

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