# Instruments to Evaluate Self-Management of Radiation Dermatitis in Patients With Breast Cancer

Michelle Pembroke, PhD, RN, OCN®, and Lynne S. Nemeth, PhD, RN, FAAN

**PROBLEM IDENTIFICATION:** Radiation dermatitis (RD) is an expected side effect of radiation to the breast and chest wall. Healthcare providers routinely grade the severity of RD without assessing its impact on quality of life for patients with breast cancer. Instruments are needed to identify a patient's ability and confidence to self-manage RD.

**LITERATURE SEARCH:** A search was conducted of published literature from 2001 to 2018 that included patients who had received radiation therapy for breast cancer. A validated instrument was used to assess RD.

**DATA EVALUATION:** Eleven instruments were identified and evaluated for assessing self-management.

**SYNTHESIS:** One instrument was identified that measured a patient's ability to self-manage symptoms. The Patient-Reported Outcomes Measurement Information System Self-Efficacy for Managing Chronic Conditions–Manage Symptoms should be considered for clinical integration.

**IMPLICATIONS FOR PRACTICE:** Using a validated instrument to assess patients' needs and ability to self-manage RD will promote personalized care plans tailored to each patient. Findings can be used to implement a patient-reported outcome measure into clinical practice, develop educational programs for RD management, and create personalized care plans.

Evidence substantiates better health outcomes for patients who actively engage in disease and symptom self-management (Chou, Kuang, Lee, Yoo, & Fung, 2016; Deshpande, Rajan, Sudeepthi, & Abdul Nazir, 2011). However, healthcare providers may overestimate an individual's skill, confidence, and ability to properly self-manage symptoms. Exclusive of surgery, most breast cancer treatments are delivered in the outpatient setting, underlining the importance of assessing a patient's ability to independently understand, recognize, monitor, and effectively manage symptoms while at home, work, or school.

Breast cancer is the most common form of female cancer. The American Cancer Society (2019) estimated that, in 2019, more than 270,000 new cases of invasive and noninvasive (in situ) breast cancer will have been diagnosed in American women and about 2,670 invasive cases will have been diagnosed in American men. Treatment for breast cancer includes one or more of the following modalities: surgery, lumpectomy (also called breast-conserving therapy [BCT]) or mastectomy, systemic therapy (chemotherapy or endocrine manipulation therapy), and radiation therapy (RT). Although the recommendation for RT depends on factors such as staging and existing comorbidities, a large proportion of newly diagnosed women with breast cancer will undergo adjuvant or neoadjuvant RT (Kole, Kole, & Moran, 2017). RT is also recommended with a breast or chest wall recurrence (Kole et al., 2017).

The goal of RT is to destroy microscopic cells and reduce the possibility of a cancer recurrence or metastasis (Iwamoto, Haas, & Gosselin, 2012). Typical RT for breast cancer is delivered five days a week, and treatment may last three to seven weeks. Unlike systemic chemotherapy side effects, RT side effects are localized to the treatment area. Inflammation of the skin, or radiation dermatitis (RD), is an expected side effect to the breast, axilla, supraclavicular, sternal, or

chest wall area. Studies have reported that 75%–100% of patients will report some degree of skin-related changes from RT (Cogswell, McGarry, & Bauer, 2018). Patients typically are scheduled for a weekly clinic visit with the radiation oncology nurse and physician for symptom management and education. Depending on the severity of RD, patients may exhibit pain and require altering of their usual activities because of RT side effects and their care. In some cases, a break or delay in RT or an RT dose reduction is warranted because of severe or intolerable RD, which can cause tumor regrowth or compromise cure (Cleary, Anderson, Eickhoff, Khuntia, & Fahl, 2017).

Currently, no gold standard exists for preventing or treating RD; therefore, treatment varies and depends on physician and facility preference (Kole et al., 2017). Studies have been conducted to examine the palliative effects of topical creams, steroids, oral nutraceuticals, laser therapy, and anti-inflammatory agents, but results are inconclusive, involve small homogeneous populations, or fall short of statistical significance (Censabella, Claes, Robijns, Bulens, & Mebis, 2016; Cleary et al., 2017; Haruna, Lipsett, & Marignol, 2017; Iwamoto et al., 2012; Miller et al., 2009; Ryan Wolf et al., 2018). A systematic review reported on the lack of significant trials to provide concrete evidence for prevention or management of RD (Chan et al., 2014). The authors were able to combine results of studies testing Wobe-Mugos® E, an oral enzyme compound containing trypsin, chymotrypsin, and papain, versus usual care, and noted limited differences; however, small sample sizes resulted in wide confidence intervals, suggesting a high level of uncertainty based on effect size (Chan et al., 2014). Therefore, studies have yet to report a definitive method or product to incorporate prevention or reduction of RD.

In clinical practice, providers use the Common Terminology Criteria for Adverse Events (CTCAE), version 4.0 or 5.0, or the Radiation Therapy Oncology Group to score the severity of RD during weekly clinic visits (Cox, Stetz, & Pajak, 1995; U.S. Department of Health and Human Services, 2010). The CTCAE terms are grouped by anatomical site. The grading system of adverse events is used to describe any unfavorable response a patient experiences related to receiving a medical treatment or procedure. However, neither grading scale evaluates how confident patients feel in managing their RT-related side effects or their ability to incorporate symptom management into daily settings, such as home life, work, and leisure activities. Adding a validated patient-reported instrument to the weekly clinic visit may enable more focused education and resources for improved patient symptom self-management.

Two previous studies were conducted at an outpatient radiation clinic by the first author to identify perceptions of the most important survivorship care topics by clinicians and patients. An investigator-developed survey was administered to radiation oncologists and nurse case managers at an academic RT clinic; radiation-related side effects were second in importance, behind only fear of recurrence (Pembroke, Nemeth, & Bradley, 2019). In addition, a qualitative study (Pembroke, Bradley, & Nemeth, 2019) was conducted with breast cancer survivors, who reported that the most common unmet need was lack of understanding and self-management of RD. The corroborating findings from the provider survey and survivors' perceptions emphasized the need to investigate clinic practices related to RD (Pembroke, Nemeth, & Bradley, 2019). Findings from these studies indicate a need for an evidence-based skin care protocol to help patients self-manage radiation-related skin changes.

## Patient-Centered Care

Since the early 2000s, the U.S. healthcare system has placed greater focus on patient-centered outcomes. In 2001, the Institute of Medicine (IOM) described the challenges of an overly complex and uncoordinated delivery of care in its report *Crossing the Quality Chasm: A New Health Care System for the 21st Century*. One of the six aims of this landmark report was to incorporate patients' wishes and desires into clinical decision making and ensure that the patient is the source of control (IOM, 2001). Five years after the publication of that report, the IOM addressed the unique needs of patients with cancer by publishing *From Cancer Patient to Cancer Survivor: Lost in Transition* (Hewitt, Greenfield, & Stovall, 2006). This report identified the failure of the U.S. healthcare system to manage cancer survivors' needs beyond the five-year benchmark from initial diagnosis. One recommendation was the provision of continuous, lifelong care for cancer survivors, as well as the anticipation of survivors' needs (Hewitt et al., 2006). This patient-centered focus has produced a new arena for researchers to develop instruments specifically aimed at measuring and evaluating outcomes from the vantage point of the patient (Deshpande et al., 2011).

Weldring and Smith (2013) summarized outcomes from this shift to patient-centered care. The authors described and defined patient-reported outcomes (PROs), patient-reported outcomes measures (PROMs), and the Patient-Reported Outcomes

Measurement Information System (PROMIS). PROs are defined as a direct report from a patient experience without subjective or objective influence from a healthcare provider (Weldring & Smith, 2013). PROMs are validated instruments designed to measure the content of PROs and can be in the form of questionnaires and surveys and measure overall quality of life or disease-specific variables (Deshpande et al., 2011; Weldring & Smith, 2013). PROMIS was initiated by the National Institutes of Health as a collaboration of healthcare scientists charged with advancing the standardization of PROs and PROMs (Weldring & Smith, 2013).

Until a gold standard for prevention of radiation-related side effects is established, particularly for dermatitis, healthcare providers should embrace the patient-centric healthcare model. By using a shared-care, holistic model, RD should be evaluated from the patient's perspective in addition to grading the severity of radiation-related skin changes, thereby treating the impact that radiation side effects have on the quality of life of each individual patient.

## Self-Management

Johnston, Rogerson, Macijauskiene, Blaževičiene, and Cholewka (2014) provided the following comprehensive definition of self-management:

> Supported self-management . . . by nurses, can, therefore, empower people to acknowledge the impact of their condition on their life, and enable them, where possible, to face the range of challenges they may have, and identify areas where they need further support, help or care . . . being given the means to master or deal with problems rather than relinquish them to others. (pp. 2, 6)

This definition supports the collaboration of a shared-care model between healthcare providers (primarily nurses) and patients. A supported self-management relationship between radiation oncology nurses and patients with breast cancer can identify deficiencies in patients' knowledge of symptom management and instill confidence in patients' decisions regarding care (Johnston et al., 2014).

The research question driving this integrative review is the following: What validated instruments exist to directly or indirectly evaluate components of self-management for patients with breast cancer experiencing RD? The significance of this review is grounded in improving healthcare delivery focused on patient-reported symptom management. By

identifying validated instruments used to assess the needs of patients with breast cancer, educational programs can be created or implemented to promote better self-management, self-efficacy, and confidence in navigating through the skin-related side effects experienced from RT.

## Methods
### Search Strategy

A systematic search was conducted of published reports of experimental and nonexperimental studies. The following five steps, described by Whittemore and Knafl (2005), were used to ensure accuracy in reporting the results of different research methodologies:

- Problem identification stage: Clear identification of the prevalence of radiation-induced dermatitis in patients with breast cancer
- Literature search stage: Literature search using database(s) and keyword combinations for breast cancer, radiation, and self-management
- Data evaluation stage: Evaluation of the quality of studies based on inclusion (and exclusion) criteria
- Data evaluation stage: Data analysis of validated instruments
- Presentation: Reporting of results

Prior to conducting the search, a medical reference librarian was consulted for guidance in database selection and keyword recommendations. This review was conducted during September and October 2018 and used EBSCOhost, PubMed, and additional Internet searching of known instruments and journal hand searching. Keywords used for searching the breast cancer population included *breast cancer* and *breast neoplasm*. The keywords used for searching RT included *radiation*, *radiotherapy*, *radiation treatment*, and *external beam therapy*. The keywords used for searching RD included *side-effects*, *dermatitis*, *radiation induced dermatitis*, *skin changes*, and *radiation dermatitis*. The keywords used for searching available psychometric instruments included *self-management*, *instruments*, *evaluation*, *psychometric tools*, *patient reported*, *symptom management*, *tools*, and *measures*. This literature search included studies published from January 2001 through October 2018 and printed in English. This date range was based on the conceptual shift of patient-centric healthcare delivery, as described in the IOM report (Hewitt et al., 2006). Included in this literature review were studies involving patients with breast cancer who had received RT and for whom a validated instrument was used. No filters were added to discern between type of breast surgery performed (mastectomy or BCT), demographics (e.g., patient age, sex, race,

socioeconomic status), and whether systemic therapy was given.

### Search Outcome

Using the keyword search combinations, a total of 166 articles were sourced from PubMed (n = 129), EBSCOhost (n = 11), and the Internet and journal hand searching (n = 26). After deleting duplicate articles (n = 6), the remaining 160 underwent title and abstract review, and 60 were excluded for not measuring RT-related side effects, including outcomes comparing chemotherapy or systemic therapy agents (n = 15); variations in radiation treatment, doses, or volumes (n = 34); or evaluation of disease-free survival, recurrence, or metastasis (n = 11). The remaining 100 articles underwent full-text review, and 59 studies were excluded for outcomes other than RD, including fatigue, cardiac variability, pneumonitis, lymphedema, or pain (n = 35). Other studies were excluded for not meeting inclusion criteria (n = 24). The remaining 41 articles were screened, and 11 psychometric instruments were evaluated for addressing one or more components of self-management that could be directly or indirectly related to management of RD. Once the 11 instruments were identified, additional hand searching, including journal reference lists and Internet searching, was conducted to retrieve the actual instrument and identify reliability and validity data. The results of this search are shown in Figure 1. Each study is referenced with its psychometric instrument in Table 1.

### Results

Skindex-16 (Schnur et al., 2012) is a dermatologic instrument of 16 questions asking, "In the past week, how bothered were you by . . . ?" Likert-type responses range from 0 (never bothered) to 6 (always bothered). Four questions assess skin conditions, seven assess emotional components, and five assess functional aspects of skin condition. This instrument is not specific to breast cancer or RD.

The European Organisation for the Research and Treatment of Cancer (EORTC) Quality-of-Life Questionnaire–Core 30 (QLQ-C30) is a 30-item, cancer-specific instrument that assesses physical, emotional, cognitive, and social functioning, and financial difficulties; the EORTC Quality-of-Life Questionnaire Breast Cancer–23 (QLQ-BR23) is a 23-item instrument specific to breast cancer and assesses components such as side effects, body image, and sexual aspects (Tan et al., 2014). Both instruments use a Likert-type scale ranging from 1 (not at all) to 4 (very much).

The Linear Analog Self-Assessment (LASA) (Sio et al., 2016) consists of five questions addressing physical, emotional, spiritual, intellectual, and overall well-being. Likert-type responses range from 0 (as bad as it can be) to 10 (as good as it can be). This instrument is not specific to breast cancer or RD;
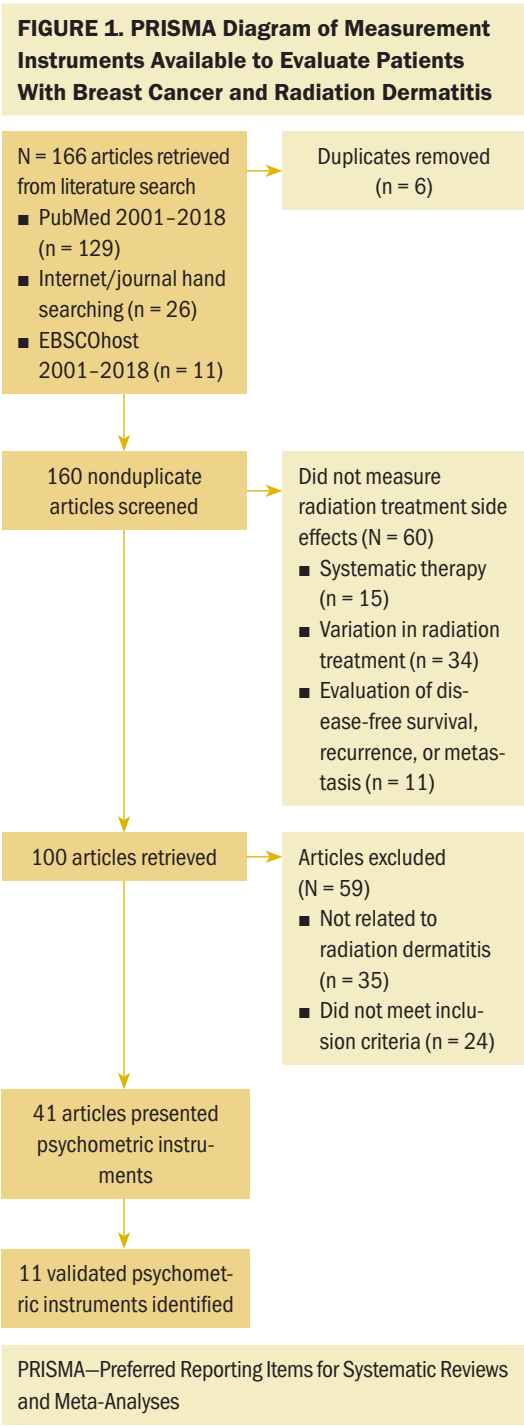
**FIGURE 1. PRISMA Diagram of Measurement Instruments Available to Evaluate Patients With Breast Cancer and Radiation Dermatitis**

N = 166 articles retrieved from literature search
- PubMed 2001–2018 (n = 129)
- Internet/journal hand searching (n = 26)
- EBSCOhost 2001–2018 (n = 11)

Duplicates removed (n = 6)

160 nonduplicate articles screened

Did not measure radiation treatment side effects (N = 60)
- Systematic therapy (n = 15)
- Variation in radiation treatment (n = 34)
- Evaluation of disease-free survival, recurrence, or metastasis (n = 11)

100 articles retrieved

Articles excluded (N = 59)
- Not related to radiation dermatitis (n = 35)
- Did not meet inclusion criteria (n = 24)

41 articles presented psychometric instruments

11 validated psychometric instruments identified

PRISMA—Preferred Reporting Items for Systematic Reviews and Meta-Analyses

**TABLE 1. Psychometric Properties of Identified Instruments (N = 11)**

| Study | Instrument | Sample | Number of Items/ Subscale | Reliability/Validity | Comments |
|---|---|---|---|---|---|
| Berthelet et al., 2004 | Skin Toxicity Assessment Tool | 27 patients with breast cancer undergoing RT | Assesses patient treatment, objective scoring of skin reaction (erythema, desquamation, exudate, and involved area), and patient-reported symptoms (itching, burning, pulling, tenderness, other) | Level of agreement between observers in subjective concerns (72%–92%); interobserver agreement in scoring (65%–98%); objective and subjective scores were significantly correlated ($p < 0.05$). | Ease of use, less than 10 minutes to complete |
| Censabella et al., 2016 | Radiation-Induced Skin Reaction Assessment Scale | 79 patients with breast cancer | Subjective (patient) and objective (HCP) assessment; patient scores tenderness, skin itch, burning, skin warmth, and effect on daily activities; Likert-type scale from 1 (not at all) to 4 (very much); HCP assesses erythema, dry and moist desquamation, and necrosis from 0 (normal) to 4 (severe). | Inter-rater reliability established in previous study; overall inter-rater coefficient = 0.76; content and face validity established | Easy to use, clear instructions, less than 10 minutes to complete; no cost to use; able to download |
| Gruber-Baldini et al., 2017 | Patient-Reported Outcomes Measurement Information System Self-Efficacy for Managing Chronic Conditions–Manage Symptoms | 1,087 patients with chronic illness; 837 with neurologic disorders and 250 with other chronic illness | 28 questions about patients' SM confidence and controlling SM's effect on daily activities; Likert-type scale from 1 (not confident at all) to 5 (very confident) | Cronbach $\alpha$ = 0.96 and comparative fit index = 0.923 | Ease of use, less than 10 minutes to complete; no cost to use; able to be downloaded |
| Halkett & Kristjanson, 2007; Halkett et al., 2012 | RT Concerns Scale | 123 women with breast cancer completed surveys at 4 time points. | 9 items assessing concerns related to RT and side effects; 9-point Likert-type scale ranging from 1 (least important) to 9 (most important) | Halkett & Kristjanson (2007): Good internal consistency (Cronbach $\alpha$ = 0.91–0.94), adequate stability over 10 days ($\bar{X}$ ICC = 0.6, SD = 0.097), content validity established; Halkett et al. (2012): good internal consistency (Cronbach $\alpha$ = 0.86) | Ease of use, estimate less than 10 minutes to complete |

**TABLE 1. Psychometric Properties of Identified Instruments (N = 11)** *(Continued)*

| Study | Instrument | Sample | Number of Items/ Subscale | Reliability/Validity | Comments |
|---|---|---|---|---|---|
| Halkett & Kristjan-son, 2007; Halkett et al., 2012 | RT Information Needs Scale | 123 women with breast cancer com-pleted surveys at 4 time points. | 22 items assess needs relating to information about treatment, planning, cost, and side effects; 9-point Likert-type scale from 1 (least important) to 9 (most important) | Halkett & Kristjan-son (2007): Good internal consistency (Cronbach $\alpha$ = 0.86–0.94), adequate stability over time ($\bar{X}$ ICC = 0.55, SD = 0.18), content validity established; Halkett et al. (2012): Good internal consistency (Cronbach $\alpha$ = 0.86) | Ease of use; estimate less than 20 minutes to complete |
| Mendoza et al., 2013 | MD Anderson Symp-tom Inventory | 1,544 patients with breast cancer enrolled from 37 institutions | 13 common core symptoms, 6 items assessing functional interference; Likert-type scale from 0 (not present) to 10 (as bad as you can imagine) | Good internal con-sistency (Cronbach $\alpha \geq 0.85$); good test-retest reliabil-ity (ICC) 1 month apart $\geq 0.76$ for all subscales | Ease of use, less than 10 minutes to complete; cost associated: $100 per provider fee plus $100 processing fee with each order |
| Sandler et al., 2018 | Patient-Reported Outcomes Version of the Common Terminology Criteria for Adverse Events Site-Specific Breast | 389 patients treated with RT (134 for breast cancer) | 78 symptoms assessed over 124 questions; 5-point Likert-type scale ranging from none/ not at all to very much/very severe | Strong content validity; previous reliability and validity established | Ease of use, about 20–30 minutes to complete; no cost to use; able to be downloaded |
| Schnur et al., 2012 | Skindex-16 | 50 patients with breast cancer | 16 items assessing symptoms of skin, emotional impact, and functioning within social interactions; Likert-type scale from 0 (never bothered) to 6 (always bothered) | Good internal con-sistency (Cronbach $\alpha$ = 0.86–0.93); test-retest reliability (0.88–0.9); content and construct validity | Permission to use required; no cost for use in academic or research settings; about 10 minutes to complete |
| Shaitelman et al., 2015 | Functional Assess-ment of Cancer Therapy–Breast, version 4.0 | 287 patients with breast cancer | 5 domains, 44 items (35 general, 9 for breast cancer); multidimensional measure of QOL that asks patients how true each item was during the past 7 days; Likert-type scale from 0 (not at all) to 4 (very much) | Version 3.0 vali-dated by Brady et al. (1997); good internal consistency (Cronbach $\alpha$ = 0.9); test-retest correla-tion coefficients = 0.85 (over 3–7 days) | Ease of use, less than 10 minutes to complete; no cost to use; able to be downloaded |

*Continued on the next page*

**TABLE 1. Psychometric Properties of Identified Instruments (N = 11) *(Continued)***

| Study | Instrument | Sample | Number of Items/ Subscale | Reliability/Validity | Comments |
|---|---|---|---|---|---|
| Sio et al., 2016 | Linear Analog Self-Assessment | 176 patients | 5 Likert-type questions assessing physical, emotional, spiritual, intellectual, and overall health during the past 7 days from 0 (as bad as it can be) to 10 (as good as it can be) | Validated in other studies | Available for download after registering with Mapi Research Trust; less than 10 minutes to complete |
| Tan et al., 2014 | EORTC QLQ-C30 and QLQ-BR23 | 170 patients with breast cancer | QLQ-C30: 30 items assessing physical, role, emotional, cognitive, and social functioning and symptoms; QLQ-BR23: 23 items assessing breast-specific symptoms: body image, sexual functioning, and side effects; Likert-type scale from 1 (not at all) to 4 (very much) | Good internal consistency (QLQ-C30: Cronbach $\alpha$ = 0.846; QLQ-BR23: Cronbach $\alpha$ = 0.873) | Permission to use required; no cost for use in academic or research settings; about 20 minutes to complete |

EORTC—European Organisation for the Research and Treatment of Cancer; HCP—healthcare provider; ICC—intraclass correlation coefficient; QLQ-BR23—Quality-of-Life Questionnaire Breast Cancer–23; QLQ-C30—Quality-of-Life Questionnaire–Core 30; QOL—quality of life; RT—radiation therapy; SM—symptom management

however, it is commonly used with other instruments to assess a patient's feelings.

The Skin Toxicity Assessment Tool (Berthelet et al., 2004) consists of a section for healthcare providers to grade the level of erythema and measure areas of desquamation (dry or moist) and presence of exudate, as well as a section for patients to assess the level of discomfort related to RD (five categories ranging from 0–5, with 0 indicating no discomfort and 5 indicating most discomfort possible). It is not specific to breast cancer; however, it was created to objectively and subjectively assess RD.

The Radiation-Induced Skin Reaction Assessment Scale (RISRAS) is a two-part instrument that assesses patient-reported symptoms and healthcare provider grading of RD (Censabella et al., 2016; Noble-Adams, 1999). Patients complete part A, which consists of four symptom questions. Likert-type responses range from 1 (not at all) to 4

(very much). Part B is completed by healthcare providers and assesses four components of RD graded from 0 (normal skin) to 4 (deep red or more than 75%–100%).

The RT Concerns Scale is a nine-question instrument that assesses patients' concerns related to radiation; three questions address side effects (Halkett & Kristjanson, 2007; Halkett et al., 2012). Responses are on a nine-point Likert-type scale ranging from 1 (least important) to 9 (most important).

The RT Information Needs Scale assesses 22 items related to patients' informational needs specific to RT. Responses on a Likert-type scale range from 1 (least important) to 9 (most important), with each item addressing whether informational needs were met, partially met, or unmet.

The Functional Assessment of Cancer Therapy–Breast (FACT-B) consists of five sections, including physical well-being (7 questions), social/

family well-being (7 questions), emotional well-being (6 questions), functional well-being (7 questions), and breast cancer (14 questions) (Brady et al., 1997; Shaitelman et al., 2015). Likert-type responses range from 0 (not at all) to 4 (very much).

The MD Anderson Symptom Inventory (MDASI) consists of 19 questions—13 address core symptoms that patients experience with cancer treatment, and 6 address symptom interference with daily functioning (Mendoza et al., 2013). Likert-type responses range from 0 (not present) to 10 (as bad as you can imagine).

The PRO-CTCAE Site-Specific Breast is a comprehensive symptom instrument that has 124 questions representing 78 different symptom toxicities, 14 of which are specific to breast cancer (Sandler et al., 2018). Most responses are on a five-point Likert-type scale, and a few are binary (yes or no).

The PROMIS Self-Efficacy for Managing Chronic Conditions–Manage Symptoms is a 28-item instrument that assesses a patient's confidence in managing symptoms (Gruber-Baldini, Velozo, Romero, & Shulman, 2017). Likert-type responses range from 1 (I am not confident at all) to 5 (I am very confident).

### Reliability, Validity, and Ease of Use

Seven instruments reported instrument reliability using Cronbach α, and the PROMIS Self-Efficacy for Managing Chronic Conditions–Manage Symptoms reported the greatest measure of internal consistency ($\alpha = 0.96$). The remaining six instruments were comparable: Skindex-16 ($\alpha = 0.86$–$0.93$), EORTC QLQ-C30 ($\alpha = 0.846$) and QLQ-BR23 ($\alpha = 0.873$), RT Concerns Scale ($\alpha = 0.91$–$0.94$), RT Information Needs Scale ($\alpha = 0.86$–$0.94$), FACT-B ($\alpha = 0.9$), and MDASI ($\alpha \geq 0.85$). Test-retest correlation coefficients were very good in Skindex-16 (0.88–0.9), the RT Concerns Scale (0.6), the RT Information Needs Scale (0.55), FACT-B (0.85), and MDASI ($\geq 0.76$).

Five instruments reported good content validity: Skindex-16, RISRAS, the RT Concerns Scale, the RT Information Needs Scale, and PRO-CTCAE. In addition, the Skindex-16 reported construct validity and the RISRAS reported face validity.

Skindex-16, EORTC QLQ-C30 and QLQ-BR23, LASA, RISRAS, FACT-B, PRO-CTCAE, and PROMIS Self-Efficacy for Managing Chronic Conditions–Manage Symptoms were easily obtainable via Internet download. Of the 11 instruments reported, one, the MDASI, charged a fee for use. All instruments could be completed within 30 minutes or less,

and eight were estimated to take less than 10 minutes to complete.

## Discussion

This study investigated available instruments used to measure components of self-management for patients with breast cancer experiencing RD. Because RD is one of the most prevalent and bothersome side effects of RT for patients with breast cancer (Kole et al., 2017; Ryan Wolf et al., 2018), it is necessary to incorporate PROs into standards of practice to identify and address patient needs and concerns during RT while symptoms of RD are acute. Addressing patient needs and concerns is one of the goals of a patient-centric healthcare system; the integration of a supportive relationship between healthcare providers and patients with breast cancer is important in developing self-management skills to reduce the negative impact of caring for cancer treatment–related side effects during the acute phase of symptom management (Johnston et al., 2014).

All 11 instruments included in the review addressed RD directly or indirectly as a condition-specific side effect, which was an expected finding based on the search criteria. Nine of the 11 instruments addressed some component of managing side effects, treatment-related logistics, the impact of school or work, and personal relationships with family and friends on self-management behaviors. Therefore, if the goal of clinical practice is to measure variables associated with only condition- or RT-related variables helping or hindering patients and families, the EORTC QLQ-C30 and QLQ-BR23 or LASA are the appropriate instruments. For practices wishing to incorporate the previously mentioned variables and add an outcomes component, such as prevention, quality of life, or cost, the RT Concerns Scale, RT Information Needs Scale, and FACT-B instruments could be considered, but the RT Concerns Scale and RT Information Needs Scale do not assess RD as comprehensively as the FACT-B.

Most of the instruments (n = 10, 90%) identified and included in this review did not incorporate questions assessing variables that are foundational in promoting and supporting self-management behaviors like self-efficacy, self-regulation, and confidence. Without assessing learned and perceived knowledge of the disease trajectory of cancer, baseline health behavior skills and aptitudes necessary for chronic disease management, and capacity to partner with healthcare providers and other sources of social support, future interventional studies will be deficient in meeting the needs of patients and providing the necessary structures for facilitating self-management behavior

development. Literature supports the importance of identifying the effectiveness of interventions to promote health behavior change and empower patients and families to self-manage chronic illnesses (Johnston et al., 2014; McCorkle et al., 2011). Therefore, if these concepts are not addressed, the recommendations for a patient-centered healthcare model stated in the IOM's report (Hewitt et al., 2006) will not be realized.

A critical component to health behavior change includes developing disease-specific knowledge and using health-promoting skills to self-manage chronic disease. Literature reports on the extensive assessment of anxiety and depression screening for patients undergoing RT, but research is lacking for measuring confidence in managing symptoms associated with RD, which, for some patients with breast cancer, can be debilitating during treatment. Hess and Chen (2014) performed a systematic review to identify research assessing psychosocial functioning in patients undergoing RT. The studies were grouped into three categories: pre-, during, and post-RT. The authors concluded functional decline in areas of anxiety, depression, or distress, with the greatest median decline for patients with breast cancer occurring during (40%) versus pre- (18%) and post-RT (26%) (Hess & Chen, 2014).

Although self-efficacy and the ability to self-manage a cancer diagnosis have been studied after active treatment is complete, further research is needed to explore confidence in managing acute side effects during RT (Foster et al., 2015). This gap highlights the need to identify individual patient self-management skills, particularly confidence, to promote useful interventions.

The only instrument with well-validated psychometric properties identified through this search designed to specifically measure a patient's confidence in his or her ability to self-manage symptoms was the PROMIS Self-Efficacy for Managing Chronic Conditions–Manage Symptoms. This comprehensive self-management instrument has a high reliability (Cronbach $\alpha$ = 0.96), has no cost to administer, and can be completed in less than 10 minutes. Although not designed specifically for patients with breast cancer experiencing RD, it can be translated and used effectively to assess a patient's confidence in managing RD-related symptoms. By combining the PROMIS and CTCAE instruments, a holistic treatment plan for patients with breast cancer can be created and delivered.

## Limitations

This study provided an understanding of available psychometric instruments used to evaluate

## KNOWLEDGE TRANSLATION

- Few instruments evaluate the ability of patients to self-manage side effects of radiation dermatitis (RD).
- Use of patient-reported instruments measuring confidence in symptom self-management can be useful in designing patient-centered interventions for management of RD.
- Radiation oncology nurses should identify patients' actual symptom management needs versus healthcare provider perceived needs when delivering health promotion education.

self-management components and variables associated with RD in patients with breast cancer. Despite the rigor used with following the Whittemore and Knafl (2005) methodological framework, limitations should be noted. The search and analysis of this integrated review was conducted by a single reviewer. Important studies may not have been included if keywords used in this search were not recognized or associated with other studies using validated instruments. It is possible that other psychometric instruments were missed because of the inclusion and exclusion criteria, such as instruments used with other cancers or illnesses that may be applicable to patients with breast cancer, older instruments developed prior to the PROMs era, instruments that have not yet been tested for reliability or validity, and studies not printed in English.

## Implications for Nursing

Healthcare providers, particularly nurses, are trained to identify patient knowledge gaps, provide resources, and educate patients about how best to manage acute and chronic healthcare conditions. By identifying the most effective instrument to measure one or more components of self-management of RD during and after RT, healthcare providers can personalize patient care plans to meet the individual needs of each patient with breast cancer. The care plans can be accomplished through educational programs if knowledge is lacking, referral to a social worker for social and family challenges, partnership with a nurse navigator or peer navigator to assist with goal setting and decision making, and identification of barriers preventing best health outcomes.

Without a comprehensive instrument to assess the many domains of self-management, the PROMIS instrument identified in this review is a useful starting point to measure confidence. Future research can lead to evaluating whether improved confidence, through individualized symptom self-management teaching during the acute phase of RD, affects anxiety,

depression, fear, and other psychosocial concerns that patients with breast cancer experience.

## Conclusion

Research continues to advance breast cancer treatments, as evidenced by the number of survivors living well beyond the five-year benchmark from diagnosis (Siegel, Miller, & Jemal, 2018). Within the past decade, a new era in clinical research has surfaced, establishing the importance of obtaining data via patient self-reporting. Healthcare providers have a responsibility to engage in partnerships with patients to promote a patient-centered healthcare model. A true collaboration between providers and patients is needed to alleviate RD symptoms, reduce the possibility of delaying RT, and provide the best possible quality of life while symptoms are acute. The primary aim of this integrative review was to identify PROMs measuring components of self-management for patients with breast cancer experiencing RD. Individualized cancer care can be achieved by focusing attention on patients' perspectives of how cancer treatment has affected day-to-day living activities. The incorporation of PROMs in clinical practice can positively enhance the patient experience of cancer treatment, decrease healthcare resources that are not needed, and promote the best long-term quality-of-life outcomes.

**Michelle Pembroke, PhD, RN, OCN®,** was a doctoral student in the College of Nursing at the Medical University of South Carolina in Charleston and a former nurse case manager at the University of Florida Proton Therapy Institute in Jacksonville; and **Lynne S. Nemeth, PhD, RN, FAAN,** is a professor in the College of Nursing at the Medical University of South Carolina. Pembroke can be reached at michellefpembroke@gmail.com, with copy to ONFEditor@ons.org. (Submitted February 2019. Accepted August 6, 2019.)

### REFERENCES

American Cancer Society. (2019). *Cancer facts and figures 2019.* Atlanta, GA: Author. Retrieved from https://bit.ly/2P7PVAK

Berthelet, E., Truong, P.T., Musso, K., Grant, V., Kwan, W., Moravan, V., . . . Olivotto, I.A. (2004). Preliminary reliability and validity testing of a new Skin Toxicity Assessment Tool (STAT) in breast cancer patients undergoing radiotherapy. *American Journal of Clinical Oncology, 27,* 626–631. https://doi.org/10.1097/01.coc.0000138965.97476.0f

Brady, M.J., Cella, D.F., Mo, F., Bonomi, A.E., Tulsky, D.S., Lloyd, S.R., . . . Shiomoto, G. (1997). Reliability and validity of the Functional Assessment of Cancer Therapy–Breast quality-of-life instrument. *Journal of Clinical Oncology, 15,* 974–986. https://doi.org/10.1200/jco.1997.15.3.974

Censabella, S., Claes, S., Robijns, J., Bulens, P., & Mebis, J. (2016). Photobiomodulation for the management of radiation dermatitis: The DERMIS trial, a pilot study of MLS® laser therapy in breast cancer patients. *Supportive Care in Cancer, 24,* 3925–3933. https://doi.org/10.1007/s00520-016-3232-0

Chan, R.J., Webster, J., Chung, B., Marquart, L., Ahmed, M., & Garantziotis, S. (2014). Prevention and treatment of acute radiation-induced skin reactions: A systematic review and meta-analysis of randomized controlled trials. *BMC Cancer, 14,* 53. https://doi.org/10.1186/1471-2407-14-53

Chou, F.Y., Kuang, L.Y., Lee, J., Yoo, G.J., & Fung, L.C. (2016). Challenges in cancer self-management of patients with limited English proficiency. *Asia-Pacific Journal of Oncology Nursing, 3,* 259–265. https://doi.org/10.4103/2347-5625.189815

Cleary, J.F., Anderson, B.M., Eickhoff, J.C., Khuntia, D., & Fahl, W.E. (2017). Significant suppression of radiation dermatitis in breast cancer patients using a topically applied adrenergic vasoconstrictor. *Radiation Oncology, 12,* 201. https://doi.org/10.1186/s13014-017-0940-7

Cogswell, J., McGarry, K., & Bauer, E. (2018). Radiation therapy. In S.M. Mahon (Ed.), *Guide to breast care for oncology nurses* (pp. 131–149). Pittsburgh, PA: Oncology Nursing Society.

Cox, J.D., Stetz, J., & Pajak, T.F. (1995). Toxicity criteria of the Radiation Therapy Oncology Group (RTOG) and the European Organization for Research and Treatment of Cancer (EORTC). *International Journal of Radiation Oncology, Biology, Physics, 31,* 1341–1346.

Deshpande, P.R., Rajan, S., Sudeepthi, B.L., & Abdul Nazir, C.P. (2011). Patient-reported outcomes: A new era in clinical research. *Perspectives in Clinical Research, 2,* 137–144. https://doi.org/10.4103/2229-3485.86879

Foster, C., Breckons, M., Cotterell, P., Barbosa, D., Calman, L., Corner, J., . . . Smith, P.W. (2015). Cancer survivors' self-efficacy to self-manage in the year following primary treatment. *Journal of Cancer Survivorship, 9,* 11–19.

Gruber-Baldini, A.L., Velozo, C., Romero, S., & Shulman, L.M. (2017). Validation of the PROMIS® measures of self-efficacy for managing chronic conditions. *Quality of Life Research, 26,* 1915–1924. https://doi.org/10.1007/s11136-017-1527-3

Halkett, G.K., & Kristjanson, L.J. (2007). Validity and reliability testing of two instruments to measure breast cancer patients' concerns and information needs relating to radiation therapy. *Radiation Oncology, 2,* 43. https://doi.org/10.1186/1748-717x-2-43

Halkett, G.K., Kristjanson, L.J., Lobb, E., Little, J., Shaw, T., Taylor, M., & Spry, N. (2012). Information needs and preferences of women as they proceed through radiotherapy for breast cancer. *Patient Education and Counseling, 86,* 396–404.

Haruna, F., Lipsett, A., & Marignol, L. (2017). Topical management of acute radiation dermatitis in breast cancer patients: A systematic review and meta-analysis. *Anticancer Research, 37,* 5343–5353. https://doi.org/10.21873/anticanres.11960

Hess, C.B., & Chen, A.M. (2014). Measuring psychosocial functioning in the radiation oncology clinic: A systematic review. *Psycho-Oncology, 23,* 841–854. https://doi.org/10.1002/pon.3521

Hewitt, M., Greenfield, S., & Stovall, E. (Eds.). (2006). *From cancer patient to cancer survivor: Lost in transition.* Washington, DC: National Academies Press. https://doi.org/10.21873/anticanres.11960

Institute of Medicine. (2001). *Crossing the quality chasm: A new health system for the 21st century.* Retrieved from http://www.nationalacademies.org/hmd/~/media/Files/Report%20Files/2001/Crossing-the-Quality-Chasm/Quality%20Chasm%202001%20%20report%20brief.pdf

Iwamoto, R.R., Haas, M.L., & Gosselin, T.K. (Eds.) (2012). *Manual for radiation oncology nursing practice and education* (4th ed.). Pittsburgh, PA: Oncology Nursing Society.

Johnston, B., Rogerson, L., Macijauskiene, J., Blaževičiene, A., & Cholewka, P. (2014). An exploration of self-management support in the context of palliative nursing: A modified concept analysis. *BMC Nursing.* Retrieved from https://bmcnurs.biomedcentral.com/articles/10.1186/1472-6955-13-21

Kole, A.J., Kole, L., & Moran, M.S. (2017). Acute radiation dermatitis in breast cancer patients: Challenges and solutions. *Breast Cancer, 9,* 313–323. https://doi.org/10.2147/bctt.s109763

McCorkle, R., Ercolano, E., Lazenby, M., Schulman-Green, D., Schilling, L.S., Lorig, K., & Wagner, E.H. (2011). Self-management: Enabling and empowering patients living with cancer as a chronic illness. *CA: A Cancer Journal for Clinicians, 61,* 50–62. https://doi.org/10.3322/caac.20093

Mendoza, T.R., Zhao, F., Cleeland, C.S., Wagner, L.I., Patrick-Miller, L.J., & Fisch, M.J. (2013). The validity and utility of the M.D. Anderson Symptom Inventory in patients with breast cancer: Evidence from the symptom outcomes and practice patterns data from the Eastern Cooperative Oncology Group. *Clinical Breast Cancer, 13,* 325–334. https://doi.org/10.1016/j.clbc.2013.02.014

Miller, R.C., Schwartz, D.J., Sloan, J.A., Griffin, P.C., Deming, R.L., Anders, J.C., . . . Martenson, J.A. (2009). Comparison of provider assessed and patient reported outcome measures of acute skin toxicity during a phase III trial of mometasone cream versus placebo during breast RT from the north central cancer treatment group (N06C4). *International Journal of Radiation Oncology, Biology, Physics, 75*(3, Suppl.), S185. https://doi.org/10.1016/j.ijrobp.2009.07.430

Noble-Adams, R. (1999). Radiation-induced skin reactions. 3: Evaluating the RISRAS. *British Journal of Nursing, 8,* 1305–1312.

Pembroke, M., Bradley, J., & Nemeth, L. (2019). A qualitative study exploring breast cancer survivors' unmet needs after completion of radiation therapy [Abstract]. *Oncology Nursing Forum, 46,* 39–40. Retrieved from https://onf.ons.org/onf/46/2/2019-congress-podium-abstracts

Pembroke, M., Nemeth, L., & Bradley, J. (2019). Radiation therapy survivorship: Healthcare providers' perspectives on education and care. *Clinical Journal of Oncology Nursing, 23,* E66–E72. https://doi.org/10.1188/19.CJON.E66-E72.

Ryan Wolf, J., Heckler, C.E., Guido, J.J., Peoples, A.R., Gewandter, J.S., Ling, M., . . . Morrow, G.R. (2018). Oral curcumin for radiation dermatitis: A URCC NCORP study of 686 breast cancer patients. *Supportive Care in Cancer, 26,* 1543–1552.

Sandler, K.A., Mitchell, S.A., Basch, E., Raldow, A.C., Steinberg, M.L., Sharif, J., . . . McCloskey, S A. (2018). Content validity of anatomic site-specific patient-reported outcomes version of the common terminology criteria for adverse events (PRO-CTCAE) item sets for assessment of acute symptomatic toxicities in radiation oncology. *International Journal of Radiation Oncology, Biology, Physics, 102,* 44–52.

Schnur, J.B., Graff Zivin, J., Mattson, D.M., Jr., Green, S., Jandorf, L.H., Wernicke, A.G., & Montgomery, G.H. (2012). Acute skin toxicity-related, out-of-pocket expenses in patients with breast cancer treated with external beam radiotherapy. *Supportive Care in Cancer, 20,* 3105–3113. https://doi.org/10.1007/s00520-012-1435-6

Shaitelman, S.F., Schlembach, P.J., Arzu, I., Ballo, M., Bloom, E.S., Buchholz, D., . . . Smith, B.D. (2015). Acute and short-term toxic effects of conventionally fractionated vs hypofractionated whole-breast irradiation: A randomized clinical trial. *JAMA Oncology, 1,* 931–941. https://doi.org/10.1001/jamaoncol.2015.2666

Siegel, R.L., Miller, K.D., & Jemal, A. (2018). Cancer statistics, 2018. *CA: A Cancer Journal for Clinicians, 68,* 7–30.

Sio, T.T., Atherton, P.J., Birckhead, B.J., Schwartz, D.J., Sloan, J.A., Seisler, D.K., . . . Miller, R.C. (2016). Repeated measures analyses of dermatitis symptom evolution in breast cancer patients receiving radiotherapy in a phase 3 randomized trial of mometasone furoate vs placebo (N06C4 alliance]). *Supportive Care in Cancer, 24,* 3847–3855. https://doi.org/10.1007/s00520-016-3213-3

Tan, M.L., Idris, D.B., Teo, L.W., Loh, S.Y., Seow, G.C., Chia, Y.Y., & Tin, A.S. (2014). Validation of EORTC QLQ-C30 and QLQ-BR23 questionnaires in the measurement of quality of life of breast cancer patients in Singapore. *Asia-Pacific Journal of Oncology Nursing, 1,* 22–32. https://doi.org/10.4103/2347-5625.135817

U.S. Department of Health and Human Services. (2010). *Common Terminology Criteria for Adverse Events (CTCAE)* [v.4.03]. Retrieved from https://www.eortc.be/services/doc/ctc/CTCAE_4.03_2010-06-14_QuickReference_5x7.pdf

Weldring, T., & Smith, S.M. (2013). Patient-reported outcomes (PROs) and patient-reported outcome measures (PROMs). *Health Services Insights, 6,* 61–68.

Whittemore, R., & Knafl, K. (2005). The integrative review: Updated methodology. *Journal of Advanced Nursing, 52,* 546–553.