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A Qualitative Analysis of Acute Skin Toxicity among Breast Cancer Radiotherapy Patients

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Abstract

Objectives—One of the most common acute side effects of breast cancer radiotherapy is treatment induced skin changes, referred to as skin toxicity. Yet no research to date has focused expressly on skin toxicity-related quality of life in breast cancer radiotherapy patients. Therefore, our aim was to use qualitative approaches to better understand the impact of skin toxicity on quality of life.

Methods—Semi-structured interviews were conducted with 20 women (Stage 0-III breast cancer), during their last week of external beam radiotherapy. Each interview was transcribed verbatim, and thematic analysis was performed.

Results—Three themes were identified based on the interview responses: First, skin changes affect multiple dimensions of quality of life. They cause physical discomfort, body image disturbance, emotional distress, and impair both day-to-day functioning and satisfaction with radiation treatment. Second, individual differences affect women's experiences. Generally African-American women, younger women, women who are not currently in a relationship, women who are being treated during the summer, and women who are more invested in their appearance are more distressed by skin toxicity. Third, women use a variety of symptom management strategies including self-medication, complementary/alternative medicine approaches, and psychological strategies.

Conclusions—Implications of results are: 1) Skin toxicity affects numerous dimensions of quality of life, and assessment approaches and psychosocial interventions should address this; 2) individual differences may affect the experience of skin toxicity, and should be considered in treatment and education approaches; and 3) participants' own creativity and problem-solving should be used to improve the treatment experience.

Keywords

breast neoplasms; oncology; radiotherapy; radiodermatitis; qualitative

One of the most common acute side effects of breast cancer radiotherapy is skin irritation [1–3], ranging from redness (erythema), to peeling of the skin (desquamation, dry or moist), ulceration, and necrosis [4, 5]. This spectrum of skin irritation has been labeled “skin toxicity” [6, 7], and it is experienced by 74%–100% of patients over the traditional 5–7 week course of breast cancer radiotherapy.

Previous qualitative research suggests that *prior* to radiotherapy treatment, “getting burnt,” is a source of worry for women with breast cancer [8], and that during treatment, skin toxicity may result in physical discomfort, emotional distress and body image concerns [9].

However, to our knowledge, no qualitative research has focused expressly on women’s experiences of skin toxicity during external beam radiotherapy for breast cancer. Therefore, the goal of the present paper was to use in-depth interviews and thematic analysis to provide a more explicit elaboration of the impact of skin toxicity. Such elaboration could serve to guide the development of future psychosocial interventions to enhance quality of life, by not only clarifying the nature of the problem, but also by elucidating the psychosocial factors and behaviors which might place patients at greater or reduced risk for skin toxicity-related suffering.

Methods

Participants

Eligibility criteria for women included: receiving radiotherapy for Stage 0–III breast cancer, English speaking, over age 18, and being willing to participate in an interview. Exclusion criteria were any comorbid major psychiatric diagnoses or significant cognitive impairment. Participants were recruited from the radiation oncology practice of a large urban teaching hospital. All participants received external beam radiotherapy in the supine position. Radiotherapy took place five weekdays per week.

Twenty-four eligible patients were consecutively referred to the study. Of these 24, twenty agreed to participate; an 83% acceptance rate. Two refused to participate due to scheduling concerns; one reported feeling overwhelmed, and one reported being uninterested. Interviews were conducted from November 2008 through June 2009. Participants were diverse in terms of demographic and medical characteristics (Table 1).

The study was approved by the Institutional Review Board, and written informed consent was obtained from all participants. None of the authors have a personal or financial conflict of interest.

Procedure

Following a description of the study by their physician, interested patients were approached by a research team member at their simulation appointment (initial treatment planning session). The team member described the study requirements, told participants that they would meet with a clinical psychologist for an interview about their skin changes, and obtained written informed consent. Interviews were scheduled during the last week of radiotherapy, anticipating that most participants would have experienced skin toxicity by then. Interviews took place either immediately before or after scheduled radiotherapy appointments in a private examination room in the radiation oncology clinic. These logistics reduced participant burden.

Interviews were digitally recorded. All interviews were conducted by the first author (JS), a clinical psychologist who does not work for the radiation oncology department, and was not directly involved in participants' medical care. At the beginning of each interview, participants were told that to protect their privacy they could choose to be referred to by name, by initials, or by a fictional name.

Interview sessions were guided conversations intended to draw out women's stories about their experience of skin changes during radiotherapy, and more specifically, stories about how these skin changes have affected their lives. In the interview, participants were first asked, "Tell me about your experience of skin changes due to radiotherapy. Feel free to say whatever comes to mind." Following that question, the semi-structured interview guide included 11 broad areas of inquiry, each of which had follow-up probes. The questions asked about: pre-treatment expectations, the course of the symptoms, effects on physical well-being, effects on emotional well-being, effects on social well-being, effects on functional well-being, body image, satisfaction with prescribed management approaches (e.g., creams), feelings about treatment interruptions due to skin toxicity, and future expectations. The last question was "Is there anything else you think I should know about what it is like to have skin toxicity during radiation treatment?" This last question helped to ensure that important topics which were not included in the interview guide were not missed [10]. These areas of discussion were based on both our clinical experience with this patient population, as well as on the broader literature on quality of life in cancer patients [11]. Interviews lasted on average 25 minutes (range = 15–35 minutes). At the end of the interview, participants received twenty dollars compensation for their participation.

Transcription

Interviews were transcribed verbatim by one of three undergraduate psychology students, supervised by DiLorenzo and Schnur. Computer entries were stored on a secure, password protected, institutional network drive. Transcription was performed using the CLAN program's [12] Transcribe (F5) Mode, which enables users to link the digitized audio record of the interview directly to the transcript. With this feature, transcribers and coders were able to click on any given line of text and hear the associated audio. Interviews were transcribed as they were completed.

Analysis

Interview responses were subjected to thematic analysis [13]. Thematic analysis is a particular type of qualitative analysis which is focused on recognizing, analyzing, and reporting repeated patterns (themes across a data set [13]). Unlike some other forms of qualitative analysis (such as conversation analysis, interpretive phenomenological analysis, grounded theory, discourse analysis, and narrative analysis) which are tied to or stem from a specific theoretical position, thematic analysis involves considerably more flexibility in that it is not tied to a specific theory or epistemology, and is compatible with numerous theoretical approaches [13].

In light of the fact that thematic analysis is so flexible, it is important to be explicit about the methodology used. On a broader level, we made two key decisions. First, we decided to provide a thematic description of the entire data set, in order to ensure the reader would get a sense of the important overall themes. We recognized the risk of losing some of the depth and level of abstraction of a more focused analysis [13]. However, we felt the benefits of having one manuscript, which a reader could potentially walk away from with a rich description of multiple aspects of the skin toxicity experience, was worth that risk. Second, we decided to primarily conduct a "theoretical thematic analysis" rather than a purely inductive one [13]. By this, we mean that the analysis was driven by our clinical and

theoretical interests in understanding skin toxicity effects on quality of life. More specifically, the analytic goals were to: describe the skin toxicity-related experiences of women undergoing radiotherapy for breast cancer and effects on generally agreed upon dimensions of quality of life (QOL) (e.g., physical, emotional, social, functional well-being); develop a better understanding of the construct of skin toxicity from the patient's perspective; guide the development of future interventions, and guide scale development. Again, we recognized that making this decision potentially influenced the resulting data. However, such an approach has benefits which we felt outweighed this possible restriction. By imposing QOL dimensions to the data, we hoped that the themes identified would be accessible to clinicians and researchers who already "speak that language," and that as a consequence, the results would be more quickly influence patient care. A third choice we made was to take a semantic approach, whereby we focused on the surface meanings of the data.

Analytic procedures were as follows. In Phase 1, all of the authors familiarized themselves with the data. Authors read the transcripts, listened to the audio recordings of the interviews, and read the notes the interviewer kept on her impressions of each interview. In Phase 2, the authors generated initial codes individually, and then met together on a regular basis (i.e., after the first 2 interviews, and then every 5 interviews after that) to discuss their initial codes. The discussions at these meetings informed future interviews. Additionally, at each of these meetings, the authors jointly determined whether we had reached saturation – whether we were at a point when no new codes were apparent in the data analysis, and where we expected that additional interviews would not change the codes identified greatly. We used an iterative sampling process. At 20 participants, data collection and analysis were stopped because no new codes were being created, and all information collected fit into one of the existing codes. Furthermore, we observed at this point that the sample was diverse in terms of key demographic and medical history factors (e.g., age, race, ethnicity, previous chemotherapy).

By the end of Phase 2, we had generated 22 initial codes. In Phase 3, the group of authors worked together to sort these codes into broader themes. In Phase 4, we reviewed and refined the themes, and checked to ensure that the data within themes was internally consistent, and that themes were clearly distinguishable from one another. At the end of Phase 4, the original 22 codes had been sorted into three primary themes, each with attendant subthemes. The entire data set was re-read to ensure that these three themes made sense in terms of the entire collection of interviews, and to recode any data that might have been missed into these themes [13].

In Phase 5, we worked as a group to define and name the themes. We wanted to communicate to the reader in a simple and easy to understand manner what we saw as the main issues associated with skin toxicity. Various options were discussed, ranging from those more traditional to health psychology research (e.g., outcomes, moderators) to those more catchy, but perhaps less informative (e.g. "what not to wear"). Our agreed upon theme names, presented below, are a balance of both types of language.

The last phase of the thematic analysis involved writing up the results, which are presented below.

Results

Three primary themes emerged in the course of the analysis: distress associated with skin toxicity, individualizing the experience, and self-management strategies. Quotations reported were contributed by various participants, but were combined in places to improve clarity of presentation.

Experiencing distress – It hurts! It's ugly! I hate it!

Across multiple dimensions of quality of life (see details below), patients were eloquent in the descriptions of their suffering.

Nociceptive/Tactile Effects—Individual participants described the nociceptive effects of skin toxicity in terms of: a) pain/discomfort (descriptors included hurt, sharp pain, shooting pains, excruciating, raw, irritation stinging, uncomfortable, tender, soreness, sensitive); b) burning/heat (like burning your stomach with an iron, on fire, hot, like when you get too much sun); c) itching (itching, like a rash); d) pins and needles under the breast; e) pulling and heaviness (heavy, ripe, tight, about to bust, swollen). In terms of tactile effects, different participants reported that when touching their breast skin, it felt: peely, rougher, harder, leathery, warmer, tougher, patchy, bumpy, scaly, and like a lizard.

Interestingly, participants also spoke about what skin changes did *not* feel like. Skin toxicity is often described to patients as similar to a sunburn (e.g., [14, 15]), yet several specifically mentioned that it did not feel like sunburn, or that it was worse than sunburn because “sunburn goes away and eases....whereas this burn just keeps getting worse,” and “you know you’ve got another three weeks to go and um, it’s not pleasant.”

Appearance—Participants described cosmetic effects of skin toxicity including skin color changes, skin texture, and distinction between the treated and untreated breast.

Regarding skin color changes, lighter skinned women most frequently used the adjectives red, pink, sunburned, tan, or brown. One participant said her breast skin became so red that “you couldn’t even find my nipple on my breast.” Another felt, “The redness highlights the unattractiveness of the breast itself.” Darker skinned women described the treated skin as “dark and ugly, too dark, like toast when it burns, black and crispy, burnt, and charcoal.” Regarding skin texture appearance, most participants described it as “flaky looking, peeling.” Regarding differences between the treated and untreated areas, participants mentioned “Well, I have two different colored breasts now,” or “One red breast and one beige breast – it’s weird!”

Skin color changes caused anxiety about other’s reactions; concern about whether others would ask for an explanation, whether they would have to reveal their cancer treatment, whether they would become a topic of office gossip; or that “it’s a signal of unhealthiness and illness and sickness.” Many participants were very anxious for the color changes to fade, and for their original skin color to “come back.” One mentioned “I just can’t wait for it to come off.” Another noted “if I knew it would stay this way forever, it would be so bad.”

Emotional reactions—Some participants mentioned emotional reactions to the appearance of the radiated breast. One woman reported feeling “upset, scared, sorry for yourself, concerned”; another said “I don’t feel attractive at all.”; and another said “Well, it’s an emotional roller coaster, you have your good and your bad days ... as your skin gets darker and uglier, emotionally it takes a toll on you.”

Others reported emotional reactions to their physical discomfort, felt their skin irritation made them more irritable and impatient, and wondered “Why does it have to happen to me? Why do I have to be going through all these things?” Other worries included developing skin cancer or skin problems as a result of the radiation, or that radiotherapy might be interrupted or discontinued due to skin reactions. In fact, treatment interruptions were experienced by half of the participants, and provoked anxiety about whether radiotherapy would still be as successful, particularly because missing treatment days seemed contrary to the instructions given in the beginning of treatment to attend radiotherapy daily.

Participants' interpretation of the interruptions were also a source of anxiety – “I must be bad off I figured if they stopped it. They wouldn't do it unless there was a real problem,” or “I thought it had gone too far. I didn't think that I was gonna heal from that.” Finally, interruptions were a source of frustration because they lengthened the overall course of treatment.

Day-to-day functioning—Discomfort related to skin toxicity also impaired aspects of day-to-day functioning. Many women had to make: a) bra changes (e.g., going braless, going without underwire, wearing undershirts underneath bras, or wearing alternatives to a bra under clothes, such as camisoles; b) clothing changes (e.g., wearing softer clothes, wearing loose shirts so the creams used did not make their shirts stick to skin, wearing old t-shirts and only black bras because some of the creams used are “oily” or “greasy,” and stain; and c) avoiding showing any cleavage due to skin discoloration. Going braless was particularly difficult for large breasted women who felt inappropriate attending church or professional events without one. Clothing choice seemed to be a particularly stressful issue in the context of special occasions (e.g., family weddings, black tie affairs). Related to dress was an issue of cost. Almost all participants mentioned out-of-pocket spending on buying new, more comfortable clothing and on replacing clothing ruined by creams.

Discomfort due to skin toxicity also impaired sleep. Participants reported difficulty falling asleep due to burning, and difficulty staying asleep due to the need to re-position throughout the night.

Radiotherapy satisfaction—Satisfaction with radiotherapy was also affected by skin toxicity. One participant felt that if she ever needed radiation in the future, she would refuse due to the burning she had felt this time. Another considered quitting treatment due to pain. She had early stage breast cancer, and said “I figured they cut the cancer out. I don't need to suffer anymore, and I'll take my chances.”

Individualizing the experience – underneath “my” skin

Unsurprisingly, there was no obvious relationship between the objective degree of patients' skin changes and their subjective reactions to those changes. The skin changes were viewed through the lens of each patient's unique characteristics and identity. Skin toxicity was not simply experienced, but was evaluated, and across patients, five particular individual difference factors emerged which influenced the degree to which skin changes affected participants' quality of life.

One potential risk factor identified was ethnicity. Although the majority of the participants (regardless of ethnicity) were upset by changes in the color of their breast, Black American women were more distressed about the extent of the color changes in their breast resulting from radiotherapy. One Black participant said “Women, I guess of darker skin tone, rarely get burned. Or we just don't lay out in the sun so much ... so this is my first time experiencing what a sunburn really is... so now I know what they mean .. but before when it was mentioned to me, I was like okay, I guess I'll just wait and see.” Other comments made were that “as opposed to someone who is much fairer, they turn red and then eventually it fades, but because I'm darker it might just stay dark.” This unfamiliarity is consistent with 2004 survey findings that the prevalence of sunburn among non-Hispanic Black women is noticeably lower than other groups [16], and may explain part of why the color changes are more distressing for Black American women.

Gendered colorist attitudes in Black American culture, where darker skin is perceived as less attractive or less desirable in women [17–19], and where there may be particular prohibitions about darkness as a result of sunburn (to which skin toxicity is often compared),

may also play a role in ethnicity effects. In her memoir *Don't Play in the Sun: One Woman's Journey Through the Color Complex* [20], Marita Golden remembers being told by her mother not to play in the sun, and writes “for my mother, darkness, blackness, in its own way was a kind of disease whose progress, in its assault on me, she felt she had to try to halt” (p. 10).

In earlier work, Ryan and colleagues [21] studied a sample of cancer patients (including breast cancer patients) undergoing radiotherapy, and found that black patients reported significantly more severe skin problems than white patients. The present qualitative findings add to the Ryan et al. study by suggesting that increased reports of skin problems may not only be related to issues such as pigmentation, but may also be in part due to Black women's evaluation of the skin changes they are experiencing, their perceptions, attitudes and beliefs about those skin changes. However, it should be noted that both the present study and the Ryan et al. study had relatively small samples of Black breast patients (5 in the present study and 10–33 in the Ryan study, depending on the analysis). Therefore much work remains to be done to elucidate racial/ethnic effects on skin toxicity.

Other demographic/environmental risk factors suggested by the responses included age, relationship status, and season. Concerning age, older participants felt that they would have been more distressed and self-conscious if they were younger, particularly if they were younger and single. This finding is consistent with literature suggesting that self-objectification, habitual body monitoring, appearance anxiety, and importance of body shape, weight and appearance decrease with age [22, 23]. As one participant said “I think that older women, most of us, we're probably okay with our bodies at this point in time, in our lives.” However, it should be noted that although older women reported being less distressed by skin changes, it was not clear whether this was in part due to their belief that they *should* be less distressed.

With respect to relationship status, being single seemed to be a source of stress. The primary concern was “it's pretty hideous and I don't have a boyfriend now, but I don't even know how I would feel in an intimate situation.” The comments about relationship status are consistent with breast cancer literature indicating that women without partners were more embarrassed about their body and worried more about their sexual attractiveness [24].

Regarding season, skin changes were more problematic for participants during spring/summer for three reasons: dress, sun/pool/beach exposure, and body odor concerns. In terms of dress, participants reported that in the winter, “you wear sweaters and shirts that cover, but I think in the summer it might affect somewhat ...if I find that you can see my skin, you can see that side being darker, I might have to change my clothing.” This concern is consistent with qualitative research on vitiligo [25], which notes increased concern about the skin condition being noticed during the summer. In terms of sun exposure, participants were worried about getting sunburned on the radiated breast because they felt it would be particularly painful or because they worried that the radiated breast was particularly susceptible to skin cancer. Additional concerns were that pool water or salt water might irritate the breast skin. Finally, because participants were instructed not to use usual deodorant during radiation, they expressed concern about body odor.

Lastly, literature on body image and cancer [26, 27] and on adult burn survivors has identified the individual difference variable of “investment in appearance” to be a predictor of emotional distress [28], body esteem [29], and body dissatisfaction [30]. In general, individuals feel more threatened by the loss of something in which they are highly invested than by the loss of something in which they are less invested. Consistent with this view, a trend was noted for women who were more invested in the appearance of their breasts to be

more distressed by skin toxicity than other women. For example, whereas one participant said, “my self-esteem doesn’t reside in my, you know, body image or my boobs, so therefore, um, it was not an issue for me,” another participant said “actually my breast is to me my most favorite part of my body” and was upset at feeling the need to cover her breasts due to skin color changes. Although almost all participants were distressed by appearance changes, there was markedly more distress in those who were more invested.

It should be noted that whereas the first theme was guided in part by the questions from the interview guide, this theme was driven by the data that emerged.

Managing - One day at a time

Radiotherapy is a unique component of the breast cancer treatment experience for many reasons, but perhaps most often noted is the schedule (5 days/week for 6 weeks), and the lack of time to heal. Surgery is a brief process, and healing begins immediately. Chemotherapy is grueling, but there are often days or weeks between infusions when one feels, if not “ok,” then at least better. But radiotherapy can seem relentless; a process of steadily worsening discomfort, steadily increasing appearance changes, and often increased stress as days go by. Perhaps because of the daily toll that radiotherapy takes, many patients use self-management strategies focused on the short-term - getting through this day, this week, this treatment. Although a wide variety of strategies were used, most had a focus on the present or the immediate future in common.

In response to the experience of skin toxicity, and all the associated quality of life impairments, participants developed a wide variety of coping strategies. Practical symptom management strategies involved: coolness (e.g., putting a cold compress on the skin, having a fan blow cool air onto the breast, putting creams in the refrigerator, taking a cool shower); placing a U shaped pillow underneath the breast at night to reduce friction; using cosmetics (applying green base to neutralize the red color); and the changes to clothing choice reported above.

Self-medication strategies directed at managing pain/discomfort included taking acetaminophen, ibuprofen, and naproxen sodium. Other self-medication strategies including using Cortaid cream to manage itching and taking sleeping pills. Some participants also used complementary/alternative medicine (CAM) approaches including aloe vera, vitamin E oil, traditional Chinese medicine, mantras, meditation, and prayer. Psychological strategies involved: imagery (typically images of coolness such as snow covered mountains or cool water), putting trust in the medical team, making something positive out of the daily trips to the radiation clinic (e.g., taking the time to notice the landscape, exploring new places to eat in the area), using distraction strategies (e.g., listening to music, focusing on work), reminders that the side effects are “what you have to do for your health”, acceptance, and reprioritizing (e.g. “you know, I pride myself, I have a good body but ... it’s not all about looks. It’s about brains too.”).

Behavioral avoidance strategies were also noted. Some participants reported trying to avoid recognizing skin changes or exposing changed skin to others - “I don’t really touch it ... You know, I just put the cream on real fast,” “it looked bad. I didn’t want to look at it,” or “I just don’t like to look at myself naked anymore.” Some women also avoided the touch of others - “you don’t want somebody to touch your breast right there because your breasts are impaired.” On a related note, one participant reported that her husband was afraid to touch her breasts during radiation for fear of hurting her.

Other management strategies were more specifically related to the radiotherapy process and clinical team. Examples included: asking questions of the treatment team, forming realistic

expectations including being flexible about treatment length (e.g., not getting your heart set on a particular end date, planning on delays); recognizing that radiotherapy “is a cumulative process ... just be prepared that the fact that you haven’t had it yet, doesn’t mean it’s not going to happen”; being prepared for skin changes – “you sort of have to mentally prepare yourself that you know your skin is not going to look as nice during radiation, expect the worst and hope for the best”; recognizing that everyone’s treatment course is unique; and trying to “take one day at a time.”

Conclusions

To our knowledge, this is the first study to perform an in-depth analysis of the experience of breast cancer radiotherapy-related skin toxicity from the patient’s perspective. The results have important implications for members of the radiation oncology treatment team, psychosocial care providers for women undergoing breast cancer radiotherapy, and radiotherapy researchers. The primary implications for each group are presented in Table 2 below. However, broadly speaking, the results revealed the following.

First, results indicated that the skin changes caused by breast cancer radiotherapy negatively affect numerous dimensions of women’s quality of life, including: physical well-being, body image, emotional well-being, functional well-being, and treatment satisfaction. These findings are consistent with empirical reports [31], anecdotal reports [2, 6, 32, 33], and make it clear that the effects of acute “skin toxicity” are far more than skin deep. Accordingly, to be truly comprehensive, any psychosocial intervention to ameliorate skin toxicity effects on quality of life should address each of these dimensions. Literature on acquired disfigurement and dermatologic toxicities has suggested using cognitive-behavioral therapeutic approaches, including social skills training and nonpharmacologic symptom management techniques [30, 31, 34]. Similarly, to comprehensively assess patients’ experience of skin toxicity, a multidimensional scale (or a combination of unidimensional scales) is required. Simply asking about physical symptoms (e.g., pain), although important, is insufficient to capture the multitude of changes in quality of life wrought by skin changes.

Second, although it is well known that certain medical factors influence skin changes (e.g., previous chemotherapy, breast size), our results revealed the critical importance of non-medical individual differences (e.g., age, race/ethnicity, relationship status, season, importance of appearance) on patients’ experiences of skin toxicity. These factors should not only be explored in future research endeavors, but should be addressed in approaches to patient education and psychosocial intervention. For example, in our own clinic, the staff has been sensitized to avoid simply using the word “sunburn” with women of color, and to instead choose a more appropriate word that resonates with the patient’s background.

Third, results indicate that patients’ own creativity and problem-solving should be used to improve their own treatment experience as well as that of future patients. Recording and disseminating the coping strategies used by patients will ensure that a shared knowledge base develops between past and current patients, and that each group of patients will suffer less than the one before. It should be noted that while many of these strategies were likely adaptive, some are concerning. For example, some of the medications (e.g., sleeping pills) / over the counter medicines (e.g., Cortaid)/ CAM treatments (e.g., aloe) used were not prescribed by the treating physician, and in some cases were not disclosed to the treating physician. Similarly, although avoidance behaviors may have served to reduce anxiety in the short-term, the long-term effects of such a strategy are unclear. Furthermore, for some women the skin continues to change even after treatment ends, and for others side-effects such as color changes may be permanent. The possible effects of long-term avoidance are concerning, and should be explored in future research.

It should be noted that like any study, ours has limitations. First, in choosing to provide a comprehensive description of the skin toxicity experience, we sacrificed examining particular themes (or subthemes) intensely and in depth. We hope that the foundation provided by this paper will inspire others to explore issues identified here in more detail. Second, we stopped data collection at 20 participants, and although we judged that saturation was reached, from a broader perspective, there is always new information to be learned. Third, although this sample was relatively diverse in terms of age and ethnicity, there was limited diversity in terms of relationship status (the majority were single and not romantically involved). Therefore, future research should consider using purposeful sampling to explore skin toxicity effects on relationships and intimacy among those involved in romantic relationships. Fourth, these interviews were conducted at the end of the acute phase of treatment, and only address acute toxicity. Future research should explore more long term effects. Fifth, all participants received a standard course of 5–7 weeks of radiotherapy. It is not clear how the results will generalize to women receiving shorter courses of radiation treatment. Finally, this paper was intended as an overview of patients' experience of skin toxicity. Each of the symptoms, individual difference variables, and coping strategies identified and touched upon here should be further explored in greater detail by both qualitative and quantitative research.

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Table 1

Sample Demographic and Medical Characteristics

	Sample size=20
Age Range: 38–84	$M = 60, SD = 12.4$
Ethnicity	
White(non-Hispanic)	55%
White(Hispanic)	20%
Black(non-Hispanic)	15%
Black(Hispanic)	10%
Education	
Post-graduate degree	35%
College graduate	20%
High school degree or partial college	30%
< High school degree	15%
Marital Status	
Single/never married	30%
Currently married	25%
Divorced	25%
In relationship/living with a partner	15%
Widowed	5%
Employment	
Full-time	45%
Retired or receiving disability	30%
Unemployed	15%
Part-time	10%
Previous breast cancer surgery	
Lumpectomy	80%
Mastectomy	20%
Prior chemotherapy	
Yes	35%
No	65%
Cancer Stage	
0	45%
I	30%
II	10%
III	15%
Highest physician-rated RTOG grade[4]	
1 = Follicular, faint or dull erythema / epilation / dry desquamation / decreased sweating	45%
2 = Tender or bright erythema, patchy moist desquamation / moderate edema	50%
3 = Confluent, moist desquamation other than skin folds, pitting edema	5%

	Sample size=20
Total radiation dose: range=4680cGy-6480cGy	<i>M</i> =5594 cGy
Number of radiotherapy fractions: range= 25–35	<i>M</i> =31

Note: RTOG = Radiation Therapy Oncology Group

Table 2

Recommendations based on interviews

Recommendations for the Radiation Treatment Team	Recommendations for Psychosocial Care Providers	Recommendations for Radiation Researchers
<i>Assess for women who may be at greater risk</i> for skin toxicity-related distress due to the moderating factors described above, and tailor patient education and problem solving efforts accordingly.	<i>Assess for women who may be at greater risk</i> for quality of life impairment due to the moderating factors described above. Psychosocial Interventions should be flexible enough to adapt to these factors. If resources are limited, interventions should perhaps be targeted to these groups.	<i>Empirical testing of the potential moderators</i> suggested here would improve our understanding of risk factors for quality of life impairments related to skin toxicity.
<i>Avoid solely using the word “sunburn”</i> to describe skin changes, as it may underestimate the experience for some, to invalidate it for others, and to be unfamiliar to darker skinned women. Instead, use a wider range of descriptors (e.g., itchy, hot).	<i>Be attuned to patients’ language choice when discussing their skin changes.</i> Very few participants used the word “pain” to describe their experience. Whenever possible, use patients’ own words during interventions.	<i>Develop a multidimensional scale</i> to assess the effect of skin toxicity on various dimensions of quality of life.
<i>Set appropriate expectations for skin changes.</i> The vast majority of women will experience skin changes during radiotherapy, and these changes tend to worsen throughout treatment. Provide this information honestly, but in a reassuring manner.	<i>Avoid suggesting images of heat</i> (e.g., sun, summer, warmth) in interventions involving imagery. Focus instead on images of coolness (e.g., cool washcloth, cool breeze, snow, mist, cool water).	<i>Assess all affected domains of quality of life, not merely the physical domain.</i>
<i>Develop and distribute a “tip sheet”</i> based on the participant-initiated coping strategies described here. Hand this out to each patient at either consultation or simulation (i.e., before treatment begins), so women can make practical preparations for the treatment. During each patient’s treatment, collect any new strategies they have found useful and add them to the list.	In any form of talk psychotherapy, <i>be aware of the multitude of effects that skin changes can have on patients’ thoughts, feelings, and quality of life.</i> Also, be aware that like many symptoms, it is the patient’s perceptions of and reactions to skin changes that are the most important intervention target. What a physician might rate as an RTOG score of 1 (mild redness) may be devastating or perceived as glaring to a given patient.	<i>Include patient-rated measures in research on skin toxicity,</i> so that the patient’s voice is reflected in the research.
<i>Provide psychosocial interventions, or make referrals to such interventions,</i> to help women manage the suffering associated with skin changes.	Participants were sensitive to and worried about the reactions of others to their skin changes. If a patient chooses to show you/talk about their skin changes, it is important to react in a <i>sensitive, non-rejecting manner.</i>	<i>Qualitative and quantitative</i> approaches could be used to further explore the influence of individual differences (e.g., culture) on patients’ experiences of skin toxicity.