Objective: Little is known about the skin-related quality of life (QOL) among women receiving external radiotherapy (EBT) and who experience breast radiodermatitis. This pilot study aimed to describe the thoughts and experiences of women experiencing breast radiodermatitis of the breast at a comprehensive community cancer program.

Methods: A printed survey was used to solicit feedback on the Dermatology Life Quality Index (DLQI) during the 5th week of EBT. An open-ended question inquired which DLQI-related issue was most important and why. A directed qualitative content analysis was conducted on the narrative responses.

Results: Twenty-eight women provided a response to the “most important” question. Sixty narratives led to the identification of 35 codes and six themes during content analysis. Themes included perspectives on having radiodermatitis, sensations caused by radiodermatitis, knowledge, and preparation for radiotherapy, prevention of radiodermatitis, emotions induced by skin changes, and physical appearance of the breast skin. Conclusions: The study results provide a glimpse into the perceptions of skin-related QOL among community-dwelling women who experienced breast radiodermatitis. Some women expressed that radiodermatitis had a profound impact on their QOL while others were surprised that EBT was easy compared to chemotherapy. Our findings parallel those found in a previous study conducted in an urban setting. Results provide insight into the thoughts and needs of women undergoing breast EBT. Assessing individual differences in skin-related QOL can provide needed information for tailoring care to the unique needs of each woman. Additional studies focusing specifically on skin-related QOL are needed.

Key words: Breast cancer, Dermatology Life Quality Index, directed qualitative content analysis, pain, pruritus, quality of life, radiodermatitis, skin toxicity
Introduction

“I hope she does better than I did. I got all burnt up!” commented the daughter of a woman with breast cancer who was about to start radiotherapy. The daughter was also a breast cancer survivor. Her haunting comment inspired our study.

Breast cancer is the most common cancer among women worldwide.[1] Many women with breast cancer require radiotherapy and a majority of these women experience radiodermatitis.[2,3] Radiodermatitis is treatment-induced dose-limiting toxicity.[4] It can lead to treatment delay or early termination, lost work productivity, wound care costs, social isolation, and altered body image.[5,6] Thus, radiodermatitis can greatly impact the quality of life (QOL).[5,6]

While many interventional studies designed to explore the efficacy of products created to prevent or manage radiodermatitis also examine skin-related QOL as a secondary outcome, till date, few studies focused exclusively on skin-related QOL in breast cancer patients receiving radiotherapy. However, two previous studies strongly informed our investigation. Schnur et al.[5] had 15 women keep a diary of their experiences during breast radiotherapy in a pilot study. Later, Schnur et al.[6] conducted a pivotal qualitative study using a semi-structured guide to conduct in-depth interviews of women with breast radiodermatitis at an urban major medical center that focused on women’s experiences of skin changes during radiotherapy and how those skin changes impacted the women’s lives. Findings of both studies are compared with and contrasted against our results.

Most cancer research studies are conducted at major medical centers in urban locations that have access to large populations when sampled supply enough power to answer important research questions. However, only 15% of cancer patients receive cancer treatment at urban major medical centers; most care occurs in community settings.[7] Therefore, it is important to conduct research exploring the perspectives of women with breast cancer in these community settings. Environmental factors such as proximity to the cancer program and access to transportation may differentially influence the perspectives of urban-dwelling versus community-dwelling breast cancer patients.

The primary aim of this study was to describe the thoughts and experiences of women with breast radiodermatitis at a cancer program in a community setting.

Methods

A qualitative analysis of the study participants’ written responses to an open-ended survey question is presented. This analysis is part of a larger, longitudinal, mixed-methods pilot study on the skin-related and global QOL among women experiencing acute radiodermatitis of the breast in a community setting.[8]
conceptual domains of this instrument (i.e., symptoms and feelings, daily activities, leisure, work and school, personal relationships, and treatment) influenced participant’s responses and informed some of the themes identified.

Ethical approval
The study was approved by the University of Utah Institutional Review Board (UIRB). A reliance agreement was created between the UIRB and the health care system affiliated with the cancer program. Only a unique participant identification number was used on each study form to enhance maintenance of confidentiality.

Results
Of the 40 main study participants, 28 women provided 60 narratives from which 36 codes were identified. Additional details about these 28 women are provided in Table 1.

Six themes were identified during data analysis—sensations caused by radiodermatitis, perspectives on having radiodermatitis, prevention of radiodermatitis, emotions induced by skin changes, knowledge and preparation for radiotherapy, and physical appearance of the breast skin. Numerical counts and percentages of codes were calculated to help elucidate the frequency of these concerns among the participants and are provided in Table 2.

Sensations caused by radiodermatitis
Thirty-two percent of the participants wrote about the physical sensations that accompany radiodermatitis of the breast. Itching, pain, and tenderness were the most commonly reported sensations.

• For me, the extreme itchiness has been the most important issue. I have been concerned and sometimes upset, because I have been unable to get consistent relief. Although I have continued with my regular activities and what I want to do, the itchiness was always “there” – difficult to completely ignore or forget. Moreover, although I realize my skin did not get this way overnight and will take time to heal, I have been concerned at how long that will actually be
• The soreness and redness hurts and keeps me from doing some things that I usually do. Not a big problem but its a constant reminder of what is and has happened to me
• The only issue of importance to me is my comfort level with the clothes I wear. This is nothing really new – wool has always itched, cashmere, silk, and fabric that does not breathe causes claustrophobia; polyester makes me sweat – “yes, cotton is the fabric of my life” says the advertising
• I feel like a grease monkey!
• It feels like I am boiling inside of my breast
• My skin does not bother me as much as the expanders do!

Perspectives on having radiodermatitis
The participants described their perspectives regarding the experience of having radiodermatitis of the breast along
a dynamic and vast continuum. Some women expressed a positive attitude regarding cancer care.

- I feel very lucky and fortunate that my cancer was found early and has not spread yet. Furthermore, I know there are many women who are not as fortunate in their diagnosis and those whom have much worse reactions to radiation
- The treatment is a little uncomfortable but if it is increasing my chances of not having a recurrence of cancer, it been just a small price to pay.

Cancer care often encroached on preexisting plans for summer vacations, travel, school, work, and family reunions. A number of women expressed having a deadline in mind when all aspects of cancer care would be completed.

- I do not want to delay my “exchange” with the plastic surgeon. I did not expect to have radiation at all so I’m months behind my schedule to get on with my life.

Similarly, some women in the study by Schnur et al.[5] felt there was a time when side effects were expected to appear and to resolve. One lady commented, “This is taking too long to recover... I’m not going to do any more [radiation]” (p. 671). [5]Another woman wondered whether her breast would stay red and sore forever. [5]

**Prevention and management of radiodermatitis**

Nine of the 40 participants mentioned an aspect of preventing or managing radiodermatitis. They were vigilant about inspecting skin in the radiation treatment field and applying prescribed creams.

- The most important issue is keeping my skin healthy and moisturized while in treatment
- Making sure that my skin improves a little bit each day so that I do not have any open sores or infection.
A number of women commented about adjusting clothing selection or physically altering clothing to enhance comfort, keep prescribed creams in place and without ruining clothing, and to avoid worsening of moist desquamation caused by clothing friction.

- I think just the right choice of clothes to wear and can make a difference of comfort throughout the day
- I am wearing my husband's old tee shirts. I do not want to ruin good clothes
- I am going to Goodwill today. I am going to buy some old tee shirts. I am going to cut the arms off and leave a big hole so that it does not rub the sores under my arm.

One woman commented about applying cream then wearing her bra over a camisole to keep the cream in place during work. Comparably, women in the study by Schnur et al. commented about having to go braless, changing from an underwire to an underwire-free bra, wearing a camisole or undershirt; or needing to wear loose clothing, only black bras, or old t-shirts because of greasy/oily skin creams. Large-breasted women described the inability to attend church and family functions such as weddings because of inability to wear an underwire bra.

**Emotions induced by skin changes**

Some women in our study were open about expressing their emotions about radiodermatitis while others hid their emotions and needs, embracing stoicism.

- How it looks like depresses me
- I keep it in. No one knows the pain I have unless I am asked about it – and then I say “I’m ok.”

This is an important finding. Rini et al. found cancer survivors with a negative social network orientation had lower health-related QOL and poorer functioning. Conversely, in Schnur et al. primary care 2009 study, one woman wrote in her diary that since she could see the radiation skin changes, she knew “they’re aiming right” (p. 672). Other women verbalized perceptions that since radiotherapy is invisible, they wondered if the treatment was being administered correctly or whether it would work. Women in Halkett et al.’s study expressed concerns about breast radiotherapy also harming their heart and lungs. A participant in the present study expressed a related concern.

- I am also concerned about what the radiation does to me. I know it’s to kill cancer, but its scary how it destroys the good tissues too. I am looking forward to the treatments being over and my body healing itself back to normal.

Many women in our study eagerly anticipated finishing radiotherapy. For most women with breast cancer, completion of radiotherapy heralds the end of nearly a year of cancer therapy.

- I am anxious to have the side effects of radiation behind me, so I am faithful in caring for my skin.

In addition to emotions directly related to skin toxicity, it is important to consider the impact of issues occurring in the patient’s life outside of the cancer experience. Two participants were widowed while receiving chemotherapy a few months before radiotherapy commenced.

- I have bigger things to worry about! I lost my husband not long ago!

One recently divorced woman needed to hold two job positions during breast cancer treatment. Many women needed to schedule their radiotherapy appointment at 7-7:30 am (i.e., before the cancer center officially opened) to avoid tardiness and potentially losing their daytime employment. One woman worried about her husband who was affected by Alzheimer disease wandering away while she was in the radiation treatment vault.

Another was reluctant to receive radiotherapy because she needed to babysit her grandchildren so that her daughter, a single mother, could work.

**Knowledge and preparation for radiotherapy**

Although each patient is taught by a radiation oncology nurse and radiation therapist, some women who experienced the most severe skin toxicity believed radiation skin changes were downplayed by the healthcare team. These women thought every breast cancer patient that receives radiotherapy develops severe skin toxicity and they recommended additional teaching before the start of radiotherapy.

- There seems to be more concern with how the skin “looks” rather than how it “feels” to the individual. Radiation skin changes probably follow a pattern on a continuum. I would have liked to have had a visual aid and descriptive of some sort to show that
- I feel an important issue is how you are going to feel. The more you know the better. Everyone is different and reacts different but if you have a really good idea how your skin is going to feel you can be prepared on how to dress and your social life.

Schnur et al. also recommended increased patient education about what to expect during radiotherapy. Halkett, Kristjanson, and Lobb explored the fears of women with breast before and during radiotherapy. They found the information given before the commencement of radiotherapy facilitated coping and alleviated fears.

**Physical appearance of the breast skin**

Only five women expressed concerns about the physical appearance of their breast or skin. This was a very important...
issue for some women. For example, a participant wondered if her affected breast would ever look normal again. She had a breast reduction surgery a few years before her breast cancer diagnosis to improve the look of her breasts. Conversely, another woman was surprised to complete radiation with minimal skin toxicity and bother.

- You should ask how the coloring of your skin is. How that affects you... You don’t ask if it is cracking, dry, bleeding – how the skin is. Are the creams helping
- I have not experienced most of the effects I was expecting. I have what amounts to a mild sunburn so far.

A woman in the study by Schnur et al.[6] in 2011 commented that dermatitis was worse than a sunburn because sunburn goes away but dermatitis “just keeps getting worse” (p. 263). Lighter skinned women talked about their skin getting red, for example, “you couldn’t even find the nipple on my breast” (p. 263).[6] Darker skinned women commented about their skin getting darker, for example, “dark and ugly, too dark, like toast when it burns, black and crispy, burnt, and charcoal” (p. 263).[6] Participants in our and Schnur et al.’s[6] study commented about radiodermatitis causing a greater need to cover up during the summer.

Discussion

We described the thoughts and experiences of women at a cancer program in a community setting who were experiencing breast radiodermatitis. Exploring the rich information provided by these women extends our understanding of QOL in this population. The 6 identified themes suggest that radiodermatitis has a significant impact on QOL.

Some of our results closely mirror those of Schnur et al.[5,6] The dimensions of QOL identified by Schnur et al.[6] (e.g., physical discomfort, body image disturbance, emotional distress, and impairment of day-to-day functioning) are like the DLQI subscales (i.e., symptoms and feelings, daily activities, leisure, work and school, personal relationship, treatment).

The participants in our study wrote about concerns not voiced by the participants in the study by Schnur et al.[6] For example, our study participants mentioned the sensation of boiling inside, the importance of selecting fabric that breathes, and concerns about future recurrence. To the authors’ knowledge, this is the first study to mention a sensation of boiling inside the breast among breast cancer patients and a preference for clothing fabric that breathes. Participants in previous studies reported a burning sensation or appearance of the skin.[6,15] Similarly, a preference for soft and loose clothing was reported in a previous study,[6] but did not include natural fabric such as cotton that breathes. Fear of breast cancer recurrence has been reported in other studies[16] and therefore is an important consideration when studying QOL in this population.

This study portrays the perceptions and experiences of women receiving breast cancer care in a community setting. To the authors’ knowledge, this is the first study with a primary outcome focusing on skin-related QOL among women experiencing breast radiodermatitis in a community setting. It was important to compare our findings in a community setting against those of Schnur et al.[5,6] in an urban setting to determine the generalizability of both sets of findings. We found many similarities and a few differences. Although our sample represents one community which has limited diversity, it may characterize much of the Midwestern U.S., providing a foundation for future studies.

We conducted a small pilot study to inform larger future studies. Therefore, the sample size was modest. Our participants provided insightful responses to the most important issue question, but they did so independently which did not allow for professional probes. Future studies should include probes.

Conclusion

Study results provide an important glimpse into perceptions of breast cancer patients who received EBT in a community setting and experienced radiodermatitis. Each person has a unique view of personal health. Our results show a broad range of responses. Several women expressed that radiodermatitis had profound impact on their QOL while others were surprised that radiotherapy was easily tolerated as compared to chemotherapy. Two important new findings were identified: A boiling sensation within the breast not on the skin surface and a preference for clothing fabric that breathes (e.g., cotton).

Future directions

Additional studies in community settings across the U.S. and the world are needed to compare against our results, including additional cultural and ethnic groups. Furthermore, studies are required to describe breast radiodermatitis among women with inflammatory breast cancer, men, and transgender women, and cancer patients as care providers.

Human subjects protection

The study was approved by the University of Utah Institutional Review Board (UIRB). A reliance agreement was created between the UIRB and the health care system affiliated with the cancer program. Only a unique participant identification number was used on each study form to enhance maintenance of confidentiality.
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Conflicts of interest

There are no conflicts of interest.

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