“Overall, I was well prepared for my radiotherapy treatment, and the reality was better than I anticipated.”

Introduction

For many years, women with breast cancer have raised with us their concerns related to skin changes that they experienced as a result of radiotherapy treatment. Women have told us about severe side-effects to their skin including blistering, weeping, and cracking which they found quite distressing.

Through our discussions with women, the main issue appeared to be that some women were not prepared for the skin changes, and found the experience distressing.

We decided to investigate the issue further and developed a background paper to help us to better understand the context, and determine whether this issue had been addressed before. We also conducted a survey of women, to try and determine whether this was an issue impacting on a significant number of women or not.

We were particularly interested to learn how often women are experiencing more severe skin changes, what information they had received prior to beginning their treatment, what information and support they were given to assist them in managing any skin changes they experienced, and any practical tips they could offer to other women.

Emails were sent to 738 women inviting them to complete an online survey, including 733 women from BCNA’s Review & Survey Group, and another 5 women who had expressed interest in the project.

Women needed to be currently undergoing, or have previously undergone, radiotherapy to be eligible to participate.

A total of 266 women completed the survey. The response rates to different questions may vary slightly, as not all women were required to answer all questions.

The survey also included qualitative questions, so women were able to tell us in their own words about their personal experiences.
Demographics

241 respondents told us they had a diagnosis of early breast cancer, while 8 women had had a diagnosis of secondary breast cancer. 17 women chose not to answer this question.

We asked women what type of breast cancer surgery they had received. Women were able to indicate as many types of surgery as applied to them. For example, some women may have initially had breast conserving surgery, and later had a full mastectomy.

The most common type of surgery amongst women was breast conserving surgery, followed by single mastectomy.

Women responding to the survey ranged in age from 20 to 79 years, at the time of their radiotherapy treatment. All states and territories were represented, with the majority of respondents from Victoria and New South Wales.

Figure 1 - Age of survey participants at time of radiotherapy treatment

Figure 2 – Location of radiotherapy treatment
Most women told us they underwent radiotherapy treatment between two and five years ago, and between five and ten years ago. Two women who completed the survey were currently undergoing radiotherapy treatment (Figure 3).

![Figure 3 – Time since radiotherapy treatment](image)

**When did you undergo your radiotherapy treatment for breast cancer?**
Survey Results

Radiotherapy related skin changes

Women were asked what kind of skin changes they experienced as a result of their radiotherapy treatment (Figure 4).

<table>
<thead>
<tr>
<th>Skin changes</th>
<th>% of women</th>
<th>Number of women</th>
</tr>
</thead>
<tbody>
<tr>
<td>Redness</td>
<td>87%</td>
<td>220</td>
</tr>
<tr>
<td>Soreness</td>
<td>59%</td>
<td>148</td>
</tr>
<tr>
<td>Changes in colour</td>
<td>57%</td>
<td>143</td>
</tr>
<tr>
<td>Burning</td>
<td>52%</td>
<td>132</td>
</tr>
<tr>
<td>Dryness</td>
<td>48%</td>
<td>121</td>
</tr>
<tr>
<td>Peeling</td>
<td>41%</td>
<td>104</td>
</tr>
<tr>
<td>Itching</td>
<td>41%</td>
<td>104</td>
</tr>
<tr>
<td>Tightness</td>
<td>40%</td>
<td>101</td>
</tr>
<tr>
<td>Blistering</td>
<td>34%</td>
<td>86</td>
</tr>
<tr>
<td>A feeling of thickened skin</td>
<td>25%</td>
<td>62</td>
</tr>
<tr>
<td>Weeping</td>
<td>24%</td>
<td>60</td>
</tr>
<tr>
<td>Cracking</td>
<td>20%</td>
<td>51</td>
</tr>
<tr>
<td>Swelling</td>
<td>20%</td>
<td>51</td>
</tr>
<tr>
<td>Scarring</td>
<td>12%</td>
<td>29</td>
</tr>
<tr>
<td>Other</td>
<td>9%</td>
<td>23</td>
</tr>
<tr>
<td>None</td>
<td>6%</td>
<td>16</td>
</tr>
</tbody>
</table>

Figure 4 – Types of skin changes experienced
Note: Women able to select more than one option to this question

While 87% of women told us they experienced redness, more than one third of women experiencing blistering, and just under a quarter experiencing weeping. One in five women experienced cracking and swelling.

“My treatment went rather well, apart from my skin burning, but not as badly as a lot of other women I saw. The side-effects are a small price to pay for another chance at life.”

Of the 23 women who selected ‘other’, skin changes they experienced included a reaction where small blood vessels appear near the surface of the skin (telangiectasias) and infection. The remaining women took the opportunity to explain their skin changes in more detail including descriptions of pain, itching or soreness which were options available to select in the question.

“My skin in my armpit cracked open in the days following completion of radiotherapy”

We asked women to tell us what their breast size and body weight was at the time of treatment, and whether they received a booster dose of radiotherapy, as this may have an impact on the skin side effects that they experienced1. We then compared each of these factors with the types of skin changes women experienced. We found that:

- Women with larger breasts (cup size D-FF) tended to experience more severe changes than women with smaller breasts

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1 Pignol, JP et al., A multicentre randomized trial of breast intensity-modulated radiation therapy to reduce acute radiation dermatitis, Journal of Clinical Oncology, 2008;26:2085-2092
- Women who told us they were overweight or obese at the time of radiotherapy tended to experience more severe changes than women who were average weight or underweight.
- Women who received a booster dose of radiotherapy tended to experience more severe changes than women who did not receive a booster dose.

“I was lucky in that side-effects were minimal for me.”

While 22% of women told us that the skin changes they experienced developed during the first few weeks of radiotherapy, the majority of women (70%) told us that these changes developed during the last few weeks of treatment (Figure 5).

Women were asked how long their skin changes lasted. While most skin changes lasted between one to six months, more than one quarter of women reported experiencing permanent damage to their skin as a result of radiotherapy treatment (Figure 6).

“The main side-effect I had was the loss of skin over the whole site and since treatment I still have a lovely suntan in that area. It has never faded.”
“After my skin recovered from the treatment, I had no reddened skin or marks on it. It was remarkable as I have very fair skin.”

We asked women what level of discomfort they experienced as a result of their skin changes, where 1 was very little discomfort, and 10 was very uncomfortable or painful (Figure 7). While almost one in five women rated their discomfort at 5, 30% of women, or nearly one third, rated their level of discomfort at 8 or more. We also asked women whether they experienced any pain relief after adopting certain skin care practices. This information is discussed in the skin management section of this paper (Figure 11).

![Figure 7 – Level of discomfort women reported](image)

**Skin management**

We asked women what steps they took to care for their skin before, during or after their radiotherapy treatment (Figure 8). Of the 253 women who answered this question, most women told us that they applied a topical cream or gel, stopped using deodorant, and/or altered their clothing in some way.

<table>
<thead>
<tr>
<th>Did you do any of the following to assist your skin before, during or after your radiotherapy treatments?</th>
<th>% of women</th>
<th>Number of women</th>
</tr>
</thead>
<tbody>
<tr>
<td>Apply creams or ointments</td>
<td>95.3%</td>
<td>241</td>
</tr>
<tr>
<td>Cease using deodorant</td>
<td>64.0%</td>
<td>162</td>
</tr>
<tr>
<td>Alter your clothing</td>
<td>61.7%</td>
<td>156</td>
</tr>
<tr>
<td>Burn dressings / gauze</td>
<td>36.4%</td>
<td>92</td>
</tr>
<tr>
<td>Cease using other usual toiletries</td>
<td>33.2%</td>
<td>84</td>
</tr>
<tr>
<td>Alter your bathing habits</td>
<td>30.8%</td>
<td>78</td>
</tr>
<tr>
<td>Apply cold packs</td>
<td>17.0%</td>
<td>43</td>
</tr>
</tbody>
</table>

![Figure 8 – Ways that women cared for their skin](image)

Note: Women able to select more than one option to this question

Of the women who applied a topical cream, the majority of women (83%) chose to use a general moisturising cream, while others opted to use a hydrocortisone cream, cream containing zinc, or antiseptic wound cream.
Of the women who reported using a specialist burn dressing or gauze, 5 women told us that they used Xeroform gauze, a sterile non-adhesive dressing commonly used in treating wounds.

Of the women who told us that they changed their bathing habits, the majority of women stopped using a soap altogether, or started using a milder soap (Figure 9).

<table>
<thead>
<tr>
<th>Altered bathing habits</th>
<th>% of women</th>
<th>Number of women</th>
</tr>
</thead>
<tbody>
<tr>
<td>Started using a milder soap</td>
<td>51.9%</td>
<td>70</td>
</tr>
<tr>
<td>Stopped using soap on treated skin</td>
<td>25.9%</td>
<td>35</td>
</tr>
<tr>
<td>Took cooler or shorter showers, pat skin dry gently</td>
<td>9.6%</td>
<td>13</td>
</tr>
<tr>
<td>Used sorbolene cream as soap substitute</td>
<td>6.7%</td>
<td>9</td>
</tr>
<tr>
<td>Did not wash the treated skin at all</td>
<td>3.7%</td>
<td>5</td>
</tr>
<tr>
<td>Rinsed skin with salt water</td>
<td>2.2%</td>
<td>3</td>
</tr>
<tr>
<td>Baths instead of showers</td>
<td>0.7%</td>
<td>1</td>
</tr>
</tbody>
</table>

Figure 9 – Women who changed their bathing habits
Note: Women able to select more than one option to this question

Of the women who reported changing their clothing habits, most women told us that they wore a post-surgery bra or a crop top with no wire, or they gave up wearing a bra altogether. Most of these women also reported wearing loose cotton tops that did not rub the skin.

“I wore a post-surgical bra during treatment. I did not wear a bra for the last week of treatment and one week after treatment.”

Women were asked how helpful the skin care actions they adopted were at assisting to protect or heal the skin. The majority of women found these actions helpful, most or some of the time (Figure 10).

Figure 10 – Helpfulness of skin care actions in assisting to protect or heal skin

We asked women how helpful these actions were at managing their pain or discomfort. Again, the majority of women reported these actions as managing pain most or some of the time (Figure 11).
Women were invited to share skin care tips that they would recommend to other women about to undergo radiotherapy treatment. The most common recommendations to other women include using a general moisturising cream in liberal amounts, while some women specifically recommended using sorbolene or aloe vera (Figure 12).

<table>
<thead>
<tr>
<th>Skin care</th>
<th>% of women</th>
<th>Number of women</th>
</tr>
</thead>
<tbody>
<tr>
<td>General moisturising cream</td>
<td>27.5%</td>
<td>58</td>
</tr>
<tr>
<td>Sorbolene</td>
<td>18.0%</td>
<td>38</td>
</tr>
<tr>
<td>Aloe Vera</td>
<td>10.4%</td>
<td>22</td>
</tr>
<tr>
<td>Wear loose soft cotton clothing</td>
<td>10.4%</td>
<td>22</td>
</tr>
<tr>
<td>Follow health professional advice</td>
<td>9.5%</td>
<td>20</td>
</tr>
<tr>
<td>Avoid soap or use alternative</td>
<td>7.6%</td>
<td>16</td>
</tr>
<tr>
<td>No bra, or wire-free alternative</td>
<td>7.1%</td>
<td>15</td>
</tr>
<tr>
<td>Cool the skin</td>
<td>5.2%</td>
<td>11</td>
</tr>
<tr>
<td>Avoid sun exposure</td>
<td>4.7%</td>
<td>10</td>
</tr>
</tbody>
</table>

“Definitely use a good pure moisturising cream like sorbolene, a non-perfumed moisturising soap, and get treatment as soon as there is ANY sign of burning”

Women were asked if they consulted a healthcare professional to help manage changes to their skin. 61% of women told us that they did, however we are unsure if this consultation occurred during their routine radiotherapy appointment, or whether a separate consultation was scheduled.
Information about radiotherapy and side-effects

“I was very happy with information given to me, and the care of my specialist who saw me each week to check on my skin”

We asked women to tell us whether they were given information about possible side-effects that occur to the skin as a result of radiotherapy. 90.8% of women told us that they did receive information, while 6% said they did not, and 3.2% of women could not remember.

“I was fortunate in having received information about what to expect, and I applied it.”

Most women reported receiving this information before and/or during their radiotherapy treatment (Figure 13).

![Figure 13 – When side-effect information was provided](image)
Note: Women able to select more than one option to this question

Most information was provided by either the radiation oncologist or the radiation oncology nurse.

![Figure 14 – Who information was provided by](image)
Note: Women able to select more than one option to this question
Of the women who selected ‘other’, six women said they were given information by people who had a previous experience with radiotherapy. Most of these were other women who had been treated for breast cancer, while two women said they acquired the information by themselves.

Most women told us that the information they were provided with listed or described the skin changes they experienced (Figure 15). This is good news, and we’re really pleased that women seem to be receiving information that is targeted to their needs and experiences.

Of the women who told us that the information they were given did not list or describe the skin changes they experienced, most women told us the severity of the changes surprised them.

“I feel I was cheated. I was told there may be some “redness”, but I didn’t anticipate the amount of blistering on my breast and collarbone.”

Women told us that they did not expect skin changes to begin so late in the course of their radiotherapy treatment, or after treatment had concluded altogether.

“I thought I had got away lightly and this came as a terrible shock – I was very depressed when I realised the side-effects were only just starting.”

Women also told us that they were not prepared for skin changes to last for a long period of time, in some cases for months or years, or to cause permanent damage to the skin.

Finally, some women told us that being warned of a sunburn-like reaction completely understated the skin changes they experienced.

“All I was told was that I might burn – like sunburn. Not the fact that my skin would peel off.”

“I was given a pamphlet. It listed side-effects e.g. a slight sunburn, but completely understated them.”
Other issues

The final question of the survey allowed women to make open-ended comments, and a range of issues were raised.

Support from medical staff
Many women took this as an opportunity to let us know how happy they were with the medical staff that treated them, including how kind and supportive they were.

“I was very well taken care of by the radiotherapy team, from the head specialist, the radiotherapy nurse and team. They were all very compassionate and caring.”

However, a number of women told us that they found radiotherapy to be a cold and impersonal experience, especially when compared with chemotherapy, where women told us they received a lot of attention and support from the medical staff.

“I felt a bit like I was on a conveyer belt; in and out of the zapping machine; not a person. I found it quite humiliating.”

Women also told us they were unhappy with the lack of medical check-up opportunities after the full course of their radiotherapy sessions was complete. Some women also told us that they felt they needed specific medical check-ups, for severe skin changes, or existing changes that worsened after the full radiotherapy course was complete, but they did not receive it.

“By the time I experienced burns, I didn’t have ready access to any health professionals, i.e. no regular appointments. All my treatment had finished and it was time to get on with life. There needs to be some follow-up after radiation, until the burn has healed.”

“I suggest that radiation oncologists and radiation technicians have mandatory exposure to patients following their treatment. This is when the worse damage appears.”

Permanent tattoos
A number of women told us they were unhappy with the permanent tattoos they received. They felt the tattoos contributed towards a feeling of being dehumanised, and were a constant reminder of their radiotherapy experience. Women suggested the use non-permanent alternatives to mark the skin, such as vegetable dye.

Fatigue and other side-effects
Women also told us that they experienced fatigue during radiotherapy, which was much worse than they had expected. Women told us that their fatigue was extreme, debilitating, and often developed towards the end of the course of radiotherapy, or even after it was complete. Some women mentioned that daily travel to the radiotherapy facility may have contributed towards their fatigue. Some women also acknowledged that it was difficult to say with certainty that radiotherapy caused their fatigue, as radiotherapy often began after completing a course of chemotherapy.

“I underestimated the effects of radiotherapy on me. I was too fatigued to work, although I had just finished aggressive chemotherapy treatment as well, so I think I was pretty whacked to begin with.”
Some women raised the issue of permanent damage to their bodies which they attributed to radiotherapy, and which causes them ongoing pain and distress. These included:

- Continuing shortness of breath
- Lymphoedema
- Breast shrinkage
- Severe pain (ribs, breast, arm pit, legs)
- Neck and shoulder problems
- Muscle weakness
- Spinal damage
- Gum and teeth issues
- Permanent loss of hair

**Travel**

Women also commented on the impact of having to travel, often significant distances, for their radiotherapy treatment. They highlighted not only the costs associated with this, but also the challenges of leaving family behind, or travelling with them.

“I had a 3 year old and a 1 year old child and finding suitable accommodation was very difficult. My dad paid for it as we couldn’t. My husband took 2 months long service leave.”

**Out-of-pocket costs**

Finally, a significant number of women told us about the out-of-pocket expenses they experienced during and after radiotherapy treatment.

Most women told us that the cost of radiotherapy treatment was the biggest cost burden. While some women received radiotherapy in a public hospital and had no out-of-pocket expenses, a number of women told us they were out-of-pocket many thousands of dollars, even after receiving rebates from Medicare and private health insurance funds. Most out-of-pocket costs were between $1,000 and $2,000; however two women told us they were out-of-pocket around $4,000.

“As I went through the private system I was out of pocket approximately $1,300. As I had it at the beginning of the year I had not reached the Medicare Safety Net until part way through my treatment.”

Other out-of-pocket costs included:

- Travel including petrol or flights for some rural women and accommodation
- Parking
- Skin care products, including creams and bandages
- Clothing, including wireless bras and loose cotton t-shirts
- Time spent away from paid employment
- Child care
- Costs associated with having lymphoedema that they believe developed as a result of radiotherapy treatment, including compression garments and physiotherapy appointments

“Accommodation for our family for eight weeks cost approximately $5,000 with some rebate from the travel and accommodation assistance scheme in NSW.”
Conclusion

Over the years, women have told us anecdotally that they experienced severe skin changes as a result of radiotherapy, including cracking of the skin, blistering, and weeping, and were not aware that this may happen. The purpose of this survey was to get a sense of how often women were experiencing these changes, and how informed women were about them.

While most women reported experiencing skin changes that are consistent with sunburn (redness, dryness, a feeling of burning), we found that 34% of women who completed the survey experienced blistering, almost one quarter experienced weeping, and 20% experienced cracking and swelling.

However, the majority of women told us that they were given information that accurately listed or described the changes they experienced. This is a good outcome, as it suggests that most women were prepared for the skin changes they experienced.

“I was very impressed with my treatment and the results from following the advice of my radiation oncologist to use the vitamin E cream ‘for the next 65 years.’ It really brought my skin back to pre-radium condition.”

Women who received information that did not describe the changes they experienced would have preferred information on the severity of changes, at what point skin changes could possibly begin to develop (including after their course of radiotherapy was complete), and how long the changes may last (including the possibility of permanent damage). Some women told us that being warned of a sunburn-like reaction was not helpful and completely underestimated the severe skin changes they experienced.

“I was shown illustrations re: the mastectomy and very clear information (written and verbal) re: the chemotherapy; but the effects of radiation were significantly downplayed. I was told ‘most women breeze through radiotherapy because the effects are so minor’.”

“I think doctors and nurses need to make it clear to women that the skin changes can be quite confronting.”

While most women told us that the skin care products they purchased did not leave them with high out-of-pocket expenses, of concern was the number of women who incurred high out-of-pocket expenses for their radiotherapy treatment. Most of these women reported an out-of-pocket expense of between $1,000 and $2,000. Two women reported a $4,000 out-of-pocket cost.

“The total cost was over $3,500 of which approximately $1,670 was refunded by Medicare.”

The main findings of this report were published in the Winter 2011 edition of The Beacon magazine. These results will be shared with relevant health professionals, breast cancer and cancer organisations, and women with breast cancer. The results will also inform the range of information that BCNA develops for women with breast cancer.

“I think a good honest information pack about the side-effects of radiotherapy and just what the skin will go through and how it will permanently look after radiation would be most helpful.”

For further information about this survey or BCNA’s radiotherapy skin changes project, please contact Annie Gayed, Policy Officer, Breast Cancer Network Australia at agayed@bcna.org.au or on Freecall 1800 500 258.