A qualitative descriptive study of patients’ experiences of a radiation skin reaction associated with treatment for a head and neck cancer

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ABSTRACT

The majority of patients receiving radiation therapy will experience a radiation skin reaction, ranging from mild erythema to severe moist desquamation. The anticipated skin reaction will vary by cancer diagnosis, dose of radiation, size of treatment field, and other treatment- and patient-related factors. Recently, research has dispelled long-held myths about avoiding skin care products prior to treatment, and the use of deodorant or antiperspirant during treatment for breast cancer and any potential for an increased skin dose with the use of skin care products. Patients no longer are restricted in using these products. Most of the research regarding skin reactions due to radiation has been conducted with women with breast cancer. No research has been found on the experience of a radiation skin reaction in patients with head and neck cancer (HNC), who often get the most severe skin reactions across all patient groups. Using the qualitative interpretive descriptive approach based on the methodological work by Thorne (1997), nine participants were interviewed about their experience of having a radiation skin reaction resulting from their treatment for HNC. Three themes emerged from the interviews, including 1) the symptom experience, 2) comparison to others, and 3) the experience of support and information. Implications include recommendations for practice and patient education.

INTRODUCTION AND BACKGROUND

The majority of patients receiving radiation therapy will experience a radiation skin reaction, ranging from mild erythema to severe moist desquamation. The anticipated skin reaction will vary by cancer diagnosis, total dose and fractionation schedule of the radiation, size of treatment field, and other treatment and patient related factors (e.g., age, sex, poor nutritional status) (Glover & Harmer, 2014; Singh, 2016). The physical changes to the skin can cause pain, itching, and burning sensations. This can have a negative effect on individuals’ activities of daily living, sleep, the wearing of clothing, movement, and physical activity, as well as mood and body image, loss of independence, self-care, and quality of life (Feight et al., 2011; Schnur et al., 2011). Most research has focused on comparison and evaluation of the effectiveness of products (e.g., lotions, creams, ointments, dressings, etc.) to prevent or reduce the severity of or manage skin reactions, but with limited evidence to support use in practice for the prevention or management of skin reactions (Bolderston et al., 2018; Ferreira et al., 2017). Literature reviews and critiques have been conducted, as well as guidelines developed on the prevention and management of radiodermatitis, to influence clinical practice (Chan et al., 2014; McQuestion 2011; Salvo et al., 2010; Wong et al., 2013). The body of quantitative research has been fraught with methodological challenges including small sample sizes, inconsistent terminology to define stages of skin reactions, variation in measurement tools, and varied outcomes assessed.

Recently, research has dispelled long-held myths about avoiding skin care products for a specified period of time prior to treatment, the use of deodorant or antiperspirant during treatment for breast cancer, and the potential for an increased skin dose due to use of skin care products. Patients are no longer restricted in the timing of applying deodorants, antiperspirants, lotions or creams prior to treatment (Morley et al., 2014; Tse et al., 2016). Despite this, practice environments have been slow to adopt these evidence-based changes (e.g., washing with gentle soap, use of deodorant/antiperspirant, application of lotions or creams prior to treatment). Inconsistencies in practice continue among clinicians and across practice environments leading to inconsistent information and support for patients undergoing radiation treatment (Bolderston et al., 2018). This can lead to a variety of patient experiences based on inconsistencies in practice.

Only two qualitative studies were identified on the patient’s experience with an acute skin toxicity from radiation treatment, but both have been in women with breast cancer (Andersen et al., 2018; Schnur et al., 2011). No research was identified regarding the experience of a radiation skin reaction specifically in patients with head and neck cancer (HNC). Within this group of patients, radiodermatitis is one of the most common side effects with up to 80% of head and neck cancer patients experiencing moderate to severe dermatitis. This side effect is a result of high treatment doses (56 to 70 Gy) to the primary site and to the unilateral or bilateral neck nodes, and the primary site or intended radiation target being in close proximity to the skin. Moderate to severe reactions occur despite the use of Intensity Modulated Radiation Therapy (IMRT) as a standard of care in this patient population, an approach that is designed to improve dose distribution (Singh et al., 2016).
Research has not focused on understanding patients’ experience, the impact the skin reaction has on one’s coping with treatment, access to information and resources, or how the skin reaction is managed from the patients’ perspective. Current recommendations about care are often based on the clinician’s perspective, guided by evidence of varied quality and clinician experience (Bolderston et al., 2018). Although the psychosocial issues faced by patients have been reported, patients’ in-depth perspectives about skin reactions have not been described (Campbell & Illingworth, 1992; Freight 2011). Sutherland et al. (2017) evaluated psychological stress in a subset of women with breast cancer who were participating in a randomized control trial of acute skin reaction severity, and found that stressed patients were twice as likely to experience a more severe skin reaction and five times more likely to develop moist desquamation. Understanding patients’ experience may lead to better interventions that are patient focused and supportive, the development of materials and information that patients can access, or recommendations about products to better manage the skin reaction.

PURPOSE

This qualitative study was conducted to address a gap in our understanding of how patients with HNC experience a skin reaction, how it affects their coping with treatment, their access to information and resources, and how the reaction is managed from their perspective.

Minimal attention has been paid to the experience of having a radiation skin reaction from the patients’ perspective as they live with the impact of the diagnosis and treatment. The current study will address a gap in the literature and raise awareness of clinical staff including specialized oncology registered nurses, radiation therapists, and radiation oncologists caring for patients undergoing treatment for HNC. It is also important to add to the knowledge that nurses and other clinicians need to inform their practice, in addition to the evidence-based research that has driven patient care management and education in radiation dermatitis in patients with HNC.

METHODS

The research question was: “From the perspective of the patient, what is it like to experience a radiation skin reaction?” Participants experiencing the phenomenon of interest were interviewed following their course of treatment. Participants were interviewed two to three months following treatment. They would have been unable to participate earlier because of pain related to oral mucositis, xerostomia (dryness), and odynophagia (pain with swallowing), making it particularly difficult for oral dialogue in an interview.

Sample and setting. Patients were accrued during their final week of radiation treatment, either from the treatment unit or during their final weekly review clinic appointment. A registered nurse or radiation therapist identifying a patient who had a radiation skin reaction at the end of treatment provided information regarding the purpose of the study using a letter of study introduction. If the patient was interested, a member of the research team met with the patient to answer any questions and obtain consent. The investigator obtaining consent did not have any clinical care relationship with the potential participant. A detailed consent form provided information regarding the study and was signed by the consenting participants. The patient was contacted four to six weeks after treatment completion to schedule an interview for approximately two to three months after their treatment had finished. Interviews were scheduled around the participant’s routine follow-up appointment, thereby not requiring additional visits to the cancer centre.

Purposeful sampling was utilized to seek participants representing demographic variation (i.e., men, women, younger and older participants, diagnosis), but whose experience and perspectives would have elements that are shared by others. This provided a homogeneous sample of patients experiencing radiation skin reactions and, conversely, a sample that was heterogeneous enough to maximize information or variation of themes that emerged from the data and ensure saturation or data adequacy (Morse, 2015; Tong et al., 2007).

Study inclusion criteria included: 1) participants 18 years of age or older who had experienced the phenomenon of interest (i.e., experienced a radiation skin reaction), 2) were able to read and verbally communicate in English, 3) had received radiation to the head and neck region, and 4) were willing to participate in the study. Exclusion criteria included any patient with: 1) recurrent cancer, 2) previously received radiation treatment for another type of cancer, 3) having palliative radiation treatment, or 4) received direct clinical care from either investigator.

Procedure. The interviews were conducted at the hospital in an outpatient clinic conference room or the inpatient unit for those patients admitted for their chemotherapy. Participants were encouraged to tell the story about their experience of having a radiation skin reaction. The initial question was, “What has it been like for you to experience a radiation skin reaction?” A semi-structured interview guide supported the elaboration of additional topics that arose from the discussion (Gillan et al., 2014). Questions also related to what patients were told to expect in terms of changes in their skin over the course of treatment, how to care for the skin reaction, how the skin reaction impacted their day-to-day life, and what they would tell other patients. Interviews ranged from 30–60 minutes per patient.

Recruitment proved to be more challenging than anticipated (see Limitations below). No new themes emerged after nine interviews. Hence, a decision was made to close the study at that point. The nine completed interviews were analyzed and the results are reported below.

Data analysis. All interviews were audiotaped and transcribed verbatim. Nvivo software was used for data management. Entire descriptions of the participants’ experience with their skin reaction were read to gather a sense of the whole. Statements were examined within the context of an individual interview and then linked together across interviews. Analysis
focused on the rich descriptions transcribed from the patient interviews and identification of themes through an in-depth analysis of the data and understanding of the participants’ perspectives, and the relationships and interpretations of the experience in order to report the data in a meaningful manner that would impact on clinical practice (Thorne, 1997; Thorne et al., 2016; Thorne, 2018).

RESULTS

Twenty-one patients were approached in the clinical area by the radiation therapists or the specialized oncology nurses. Fourteen agreed to be contacted by one of the researchers to hear more about the study and consented to be interviewed. Three could not be reached to schedule an interview and one withdrew from the study due to the timing of the interview. Ten participated in an interview, but one interview was not included in the analysis due to technical difficulties with the recording.

Demographics. The demographic results are presented in Table 1. Seven men and two women were interviewed, aged from 50 to 79 years. Seven participants were Caucasian and two were of Chinese descent. Diagnosis included squamous cell carcinomas of the oropharynx (base of tongue) and hypopharynx, glottis, parotid gland, and nasopharynx. The majority (8) received 70 Gy / 35# of once-daily primary radiation for advanced disease. Two participants received concurrent chemoradiotherapy. Six of the nine developed confluent moist desquamation. Three had extensive dry desquamation or patchy moist desquamation. Age distribution reflected the distribution of patients with HNC who are seen at the cancer centre. All were married and had either high school or college/university education.

Interview Data—Themes

The results are presented as themes identified from participants’ data. Three main themes emerged from the interviews, including 1) the symptom experience, 2) comparison to others, and 3) the experience of support and information. The themes are numbered for clarity of presentation, but do not reflect a linear conceptualization by the participants or researchers, or a hierarchical order.

Theme 1: The Symptom Experience

Study respondents identified the skin reaction as one of multiple symptoms experienced during treatment. They also experienced oral pain, xerostomia/oral dryness, difficulty eating and swallowing, fatigue, loss of appetite, weight loss, and other concerns related to the side effects of treatment. They tended to downplay the overall experience of having a skin reaction in comparison to other symptoms that began to develop during the course of treatment; it was one of many symptoms and issues with which they had to deal. They recognized that while the skin reaction was bothersome and worsened over the course of treatment, the overlay of other symptoms and the overall experience of treatment had a greater impact on the distress they felt while going through treatment.

For most, the skin reaction began with changes at three to four weeks into treatment. The changes to the skin on their neck and in the treatment field were identifiable in degrees over the remainder of treatment. Most developed confluent moist desquamation. A couple did not have any reaction until the end of treatment when other symptoms were more severe.

It was uncomfortable, but it was the least of my problems going through radiation.

I don’t think it was all that bad for me because I didn’t get a reaction until the end of treatment.

Participants described other symptoms associated with the skin reaction including pain. Increasing pain marked the point when their skin reaction accelerated during the fifth week of treatment. Several described the pain by weeks six and seven as ‘very serious’ and preventing them from going out. When not at the cancer centre or travelling between home and treatment, participants did not go outside of their home due to the discomfort from the skin reaction, the need forointments or dressings, as well as self-care for other treatment-related symptoms. For those using ointments but trying to avoid dressings during the daytime, they often preferred to wear a t-shirt or undershirt with the neck cut out to avoid contact of clothing close to their skin reaction. The look of the skin reaction and how they had to adapt clothing impacted on how comfortable they were going out in public for any reasons other than to attend treatment.

As treatment progressed the skin reaction intensified. The most significant impact to patients was the disruption to their sleeping. Several could not sleep in their bed and lay in a lounge chair or propped themselves up on the sofa throughout the night during the remainder of treatment and the initial weeks following treatment.

I had a hard time sleeping at night. I had to sit up in bed. I couldn’t lay on my side because that would hurt.

At nighttime if I didn’t pay attention, I woke up almost every time it (my neck or skin) unintentionally touched the blanket.

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Other participants described the symptoms they felt during the healing phase following the end of treatment. They described the sensation of tightness or pulling of the skin on the neck.

*It was very cautious about moving because of when you move and it is starting to heal, it pulls.*

*I sat in the chair most of the time during my healing.*

**Theme 2: Comparison to Others**

Participants were very cognizant of other patients in the waiting room, the radiation nursing clinic, and clinic review areas and seeing those with various degrees of skin reactions. They were aware of the need for ointment and dressings or some type of coverage over their face and neck. Some participants compared themselves to others as a way of normalizing their experience or gauging what they might later experience based on other people’s skin reactions. For many, comparison with others was self-affirming, that their skin looked similar to others at the same phase of treatment, and they were ‘ok’ or ‘not as bad off’ as others were.

*I kept noticing all the other patients going by and seeing all the redness and sores and everything and thinking am I going to go through that?*

*I noticed other patients who were having the same thing and theirs was a lot worse than mine.*

*I don’t think I had it [skin reaction] bad compared to other people.*

**Theme 3: The experience of Support and Information**

Overwhelmingly, participants said they would advise others to listen to the healthcare team and follow their advice and instructions. They felt listened to and well supported in the management of their symptoms including the skin reaction. They framed their comments as advice they would give to other patients, but they had minimal advice for clinicians. Keeping a positive self-attitude was advice for other patients also emphasized as important by participants.

*Be prepared. It’s coming, it’s going to be painful and you have to take a positive attitude.*

*Make sure you use the moisturizer every day.*

*Just moisturize, moisturize, moisturize.*

Participants also emphasized the importance of timing of information. Participants felt that the clinical team would monitor, notice changes, and make suggestions. Providing information as the skin reaction changed was helpful rather than getting too much information upfront about future changes.

*Pay attention to what they are telling you.*

*It was much better than giving me too much information at the beginning because it is overwhelming. It was so wonderful to have the team address my specific needs in a specific time.*

**STUDY LIMITATIONS**

One limitation of the study may be the lack of female participants in the study. While the ratio of men to women receiving treatment for head and neck cancers is 2:1 or 3:1, it would have been helpful to hear more from women who may experience a reaction in a different way from men.

Recruitment proved more challenging than initially anticipated. While eight to 12 patients complete head and neck cancer treatment each week at the cancer centre, only 25 patients agreed to be contacted to receive more information or provided consent to contact to arrange an interview. The clinical setting is very busy and the identification of potential patients for non-treatment-related research studies may not be the priority of busy clinicians. Many patients who were approached were not feeling well enough to consider joining a study and some who had consented were later unable to participate. Reasons for later declining the interview, included patients feeling too unwell to participate, living at a distance or difficulty coordinating an interview with a clinic appointment and avoiding multiple trips to the hospital during their early recovery period. While telephone interviews may have been a useful strategy to increase participation, many head and neck cancer patients have difficulty talking over the telephone initially post treatment.

**DISCUSSION AND IMPLICATIONS**

This study is the first qualitative study specific to patients’ experiences of a radiation skin reaction associated with treatment for a head and neck cancer. While other qualitative studies have been conducted with patients with HNC, the focus in those studies was on the overall experience or impact of receiving radiation treatment and the symptom experience during and after treatment (McQuestion & Fitch, 2016; Molassiotis & Rogers, 2012; Wells, 1998, 2007).

The radiation skin reactions experienced by the participants were one of several side effects identified, but not the focus of a more in-depth understanding of the specific symptom. Patients with HNC experience the radiation skin reaction in context of multiple other severe and impactful symptoms, including oral pain, mucositis, odynophagia, altered taste, difficulty eating and swallowing, loss of appetite, weight loss, dehydration, fatigue, etc. Haisfield-Wolfe (2012) identified a common pattern of 11 problematic symptoms that patients with HNC experienced over the course of treatment. While other qualitative studies focused on the overall experience or impact of receiving radiation treatment and the symptom experience during and after treatment (McQuestion & Fitch, 2016; Molassiotis & Rogers, 2012; Wells, 1998, 2007), this study is the first qualitative study specific to patients’ experiences of a radiation skin reaction associated with treatment for a head and neck cancer.

Participants in this study tended to downplay the experience of the skin reaction in context of other progressing and more debilitating symptoms, living day to day with the skin reaction had a significant impact on participants. Pain, discomfort, the need for ointments and dressings, changes in normal routines and sleep disruption, especially at night, caused considerable impact. Participants compared themselves to others as a marker of how well they were managing with their own experience. Remaining at home, other than travelling for treatment, was a result of self-care for the skin reaction, which required repetitive applications of lotions, creams or ointment and/or dressings and in context with self-care needs related to other
symptoms. With daily treatment lasting from four to seven weeks, this could have the potential to create or add to a sense of social isolation in some patients with fewer social supports or resources.

Sleep was also affected with patients waking frequently due to pain or discomfort from the skin reaction or having to change routines including moving from a bed to a lounge chair to sleep. Acute and chronic sleep disturbances have been identified as one of the top five risk factors for distress and can lead to daytime fatigue, irritable mood, and cognitive impairment (Van Hoose et al., 2015). Sleep disturbances should not be overlooked in this patient population including the impact of the skin reaction.

Studies in women with breast cancer have identified that the radiation skin changes affect their quality of life with challenges in day-to-day functioning including clothing changes and sleep (Schnur, 2010). Difficulty falling asleep was also related to symptoms of pain and burning. The frequent need to reposition also caused difficulty in staying asleep. Schnur, Ouellette, DeLorenzo, Green and Montgomery (2011) interviewed 20 women to gain an understanding of the impact of a skin reaction on quality of life and concluded that “the effects of acute skin toxicity are far more than skin deep”.

Listening to the treatment team and adhering to their advice was perceived to be very important by these patients. Advice to other patients included staying positive, moisturizing the skin, and paying attention to what the team advised. A study of patient preferences for instructional reinforcement regarding the prevention of radiation skin reactions reported that verbal and video reinforcement was preferred over written materials (Laszewski et al., 2016). While the participants in this study did not identify a particular format for providing information to be most important, patients are provided with written materials, videos, individual teaching, and facilitated group classes where advice about managing a skin reaction is emphasized. They also have daily assessment and weekly review and advice by the radiation therapists and registered nurses respectively. Verbal and written resources may be the standard of clinical practice in most settings, but the use of video, virtual or other technologies should be considered as options to address the needs of patients.

**IMPLICATIONS FOR PRACTICE AND EDUCATION**

Patients with head and neck cancer undergoing radiation may not feel the severity of the skin reaction across the course of treatment in the same way that other patients with different diagnoses and radiation treatments may experience, due to the overlay of multiple other symptoms or side effects over the course of the acute radiation treatment and during recovery. It is important for clinicians to understand and recognize that living day to day with a skin reaction is significant despite patients often downplaying it. The team should also recognize the skin reaction as one of a cluster of symptoms that patients experience and should address it as an important symptom to recognize and manage. Patients may benefit from procedural and management information, as well as hearing about the experience of other patients and what they have told us has been helpful. This information may include the timing and pattern of radiodermatitis symptoms, the importance of ensuring the skin reaction is recognized and managed, the impact on day-to-day life, managing at home with self-care and potential social isolation, the impact of the skin reaction on sleep and helpful strategies, the overlay of other symptoms, the way patients compare themselves to others and an emphasis on the importance of information and support. Integrating patients’ experiences into patient education materials may be helpful along with traditional evidence-based management advice.

Virtual education has and will increase, as a result of patient volumes, pandemic planning, and operational or fiscal resource challenges. However, access to clinical team members and nursing care will continue to be critical to patient-clinician interactions, assessment, and support for patients with radiation skin reactions and within context of the multiple symptom clusters that patients with HNC experience. Ensuring these interactions occur may have an impact on patient flow, clinic design and roles within radiation treatment departments and should be in addition to virtual patient education and patient support through ongoing or follow-up contact.

The prevalence of severe skin reactions has also changed over time. Practice has changed to reflect a greater focus on earlier intervention, use of specialized dressings that may remain in place during treatment and reducing skin trauma, improved patient education materials, and the development of preparatory group psychoeducation classes. Conscientious daily skin assessments on the treatment unit, as well as weekly assessment in radiation review can improve this experience for patients.

Current practice no longer restricts the timing of application of products (Morley et al., 2014; Tse et al., 2016). This results in patients being encouraged to clean the intact skin with soap and water and use lotions, creams, ointments, and dressings on their skin prior to treatment. Patients no longer need to suffer with discomfort, pain, and skin tightness, as happened when they were told to avoid products for an arbitrary period of time prior to treatment (Morley et al., 2013; Tse et al., 2016). Despite evidence to change practice, inconsistencies still continue across practice environments and among clinicians, leading to misleading information and support for patients undergoing radiation treatment. (Bolderston et al., 2018). Organizational clinical practice guides based on reviews of the literature and guideline development can be effective in changing practice across clinical settings and improving the experience and expectations of patients having skin reactions as a result of their radiation treatment for head and neck cancer (Oncology Nursing Society [ONS], 2020). Clinicians’ awareness of current literature, standards, and practices, as well as helping patients and families know what to expect will have a positive impact on patients’ experience with a radiation skin reaction during and after their treatment for HNC.
REFERENCES


