



Investigating the Impacts of Perianal Skin Cancer on Patient Quality of Life

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ABSTRACT

Published Online : January 07, 2025

Perianal skin cancer, while rare, can have severe consequences on patient quality of life. This study sought to address this question by examining patient lived experience, social impact, psychological symptoms, and perceived informational needs following a diagnosis of perianal skin cancer. Mixed methods enabled contextualization, exploration, and illumination of pertinent patient issues. Results indicated that stigma, communication, psychological and physical effects, and concern for survival may impact patient care. Psychometric data support these findings. Patient informational needs suggest a reduction in the perceived frequency of all needs and a strong preference for digital over face-to-face information provision. As a truly patient-centered study, this paper provides an important starting point for the consideration of psychosocial support for perianal skin cancer patients. The outcomes are disseminated across clinical policy, offering highlighted points of consideration.

Perianal skin cancers are rare. They are rare enough that, in general, the evidence base lacks the larger studies and data that could enable more consistent practice worldwide. This is the first patient-centered investigation of the impacts of perianal skin cancer on quality of life and patient well-being, and it is the first patient study to cascade into policy amendment within the United Kingdom, notably within the clinical unit. This study provides concrete, specific outcomes related to patient experience and clinical need, and suggests both the generic nature of the support available to assist these patients and the lack of productive practice that could be molded and strengthened from it. 1

KEYWORDS:

Skin Cancer, Patient Quality, clinical policy

1. INTRODUCTION

An uncommon malignancy, perianal skin cancer is increasing in incidence. The disease can be physically and psychologically challenging for patients. Defining characteristics of perianal skin cancer are its location, relationship to the perianal glands, and positivity. Patient survival is related to cancer stage, and the risk of metastases is mainly clustered in risk factor-positive groups of early-stage patients. However, we define patient quality of life as burning in an area that is hard to reach. Topical therapies are mainstays of treatment due to anatomic complexities, and multiple treatment modalities allow for cure. Although oncologic outcomes are crucial to patient care, it is increasingly recognized that as treatment intensifies, maintaining or even enhancing patients' quality of life is also an essential aspect of care. Given the low prevalence of perianal skin cancer, the association between this malignancy

and any potential decreases in quality of life remains largely unstudied. Given the profound, multilayered stigma, immediately decreasing the death rate from this rarely lethal malignancy seems prudent. In the absence of studies to demonstrate a possible genetic predilection or a happier subset of patients with these perianal malignancies, our focus must be on enhancing the quality of life for this population. Therefore, the purpose of this qualitative study is to determine the implications of perianal skin cancer on quality of life. In this study, our participants suggest when and how patient feedback can lead to quality of life improvements. 2

2. UNDERSTANDING PERIANAL SKIN CANCER

Perianal skin cancer is a heterogeneous group of cutaneous neoplasms located within the anal margin and anal canal. It is usually classified based on the histopathology of the lesion. The most common subtype is squamous cell carcinoma, accounting for 7% of all cases of squamous cell carcinoma and more than 80% of anorectal squamous cell carcinoma. Other histologies reported include basal cell carcinoma, Kaposi sarcoma, extramammary Paget disease, malignant melanoma, Merkel cell carcinoma of the anus, adnexal tumor

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**Cite this Article: Aliaa A. Abdulqadir (2025). Investigating the Impacts of Perianal Skin Cancer on Patient Quality of Life. International Journal of Clinical Science and Medical Research, 5(1), 23-29*

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malignancies, and adenosquamous carcinoma. Because of the low incidence of perianal skin cancer, most data available are based on single-institution experiences; consequently, doubt still persists about the natural history of this disease. In line with this, the choice in terms of surgical approach is still debated, as is the need for adjuvant chemoradiation protocols. Both the diagnosis and treatment are often performed by specialists who have little experience, as it is unlikely that patients routinely present to the clinic with perianal skin cancer, especially in advanced cases. A precise diagnosis is crucial for deciding the appropriate treatment and the potential need for systemic or adjuvant therapy. Perianal lesions are diagnosed with physical examination, anosopic examination, a tissue biopsy of the mass, colonoscopy, and positron emission tomography computerized tomography scan. Finally, it may be necessary to perform a magnetic resonance imaging of the pelvis to determine the local stage and resectability of the tumor. If biopsy results are inconclusive, reflecting the depth of the biopsy steeping in the dense keratin, an en bloc surgical resection could be done whenever possible, both for the histological diagnosis and to avoid the risk of local or systemic neoplastic dissemination.

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2.1. Epidemiology and Risk Factors

Perianal skin cancer is by no means a rare disease as its incidence increases worldwide. Although solid statistical data are scarce, a more comprehensive review could provide a glimpse into the problems that may outgrow the peculiar care but unforeseen experience from three decades. Awareness of the relationship between sun exposure and sunburn blistering at a young age is likely to contribute to the development of many skin cancers as the incidence of cancer has increased in the last 50 years. In relation to all cases, more patients with T1 have been diagnosed, as the majority of the presented cases are T1, followed by T2, T3, and T4 in this order. The disease is more common in women. In this review, the sex ratio of male to female is approximately 1:1. The highest incidence rates occurred in Australia/New Zealand and North American countries, which corresponded to the best survival rates in these areas. Although most cancers are most prevalent in males, the opposite applies here. For example, data show an incidence of 56 new cases per year in men and 62 cases in women, corresponding to an age-standardized incidence rate of 0.02 and 0.03 per 100,000 elderly people. Factors related to the prognosis of the affected non-SQ and SQ carcinoma other than usual carcinoma are currently debatable and their significance is unclear due to the scarcity of research fully devoted to this topic. Regarding the age at diagnosis, this overview seems to differ according to the cancer that is developed. It is noteworthy that those diagnosed with Bowen's disease are the youngest, meaning the absence of regional or far-reaching influences, which is possible, as this type of cancer is associated with increased sunburn and a more aggressive form of the disease. The higher frequency is in the elderly in the case of the most fantasized, the BCC. A

study suggests that the average age at diagnosis for ACC involved in the perianal-SCC is around 60 years. 4

2.2. Clinical Presentation and Diagnosis

Given the patient impacts, early recognition is crucial. Perianal skin cancer can present in various ways. Initial signs may be nonspecific, leading to delayed diagnosis. Pigmentation, bleeding, itching, and other changes should be evaluated. Clinical signs are not specific, so diagnostic tools like biopsies are important. Clinical history and symptoms should be considered carefully. Additional diagnostics like imaging can provide essential information. Collaboration between specialties is vital for proper care planning. Biopsies and topical treatments are acceptable initial therapies. Communication between healthcare professionals is crucial. A focused guide in skin cancer is intriguing for future analysis. 5

3. QUALITY OF LIFE IN ONCOLOGY

Quality of life (QoL) is a fundamental topic in oncology. Cancer and its treatments have serious effects on multiple domains, producing clinical symptoms and psychosocial stressors. QoL is a multidimensional assessment of people's lives based on their culture and personal experiences. It is distinct from health-related QoL, which is the perception of one's well-being in relation to their goals and concerns. Measurement of health-related QoL is necessary for evaluating treatment results. QoL outcomes complement traditional endpoints in clinical scenarios. The psychological impact of cancer diagnosis and treatment affects multiple domains of QoL. Domains of QoL assessment include physical, psychological, social, and spiritual domains. Factors influencing QoL include physical symptoms, emotional distress, social support, caregiver burden, finance, and access to care. QoL varies during different phases of the patient's life. Therapeutic interventions can impact QoL both negatively and positively. 6

3.1. Concepts and Measurement

Research in the field of oncological quality of life (QoL) has produced a plethora of measurable outcomes, investigating different treatment trajectories and various patient populations. Quality of life is also an important, although indirect, surrogacy outcome measure. QoL measurements enable the collective assessment of the combined treatment and support approach received alongside cancer services, and the resultant physical, emotional, social, functional, and spiritual capacities and well-being of oncology patients. The collection of consistent, comprehensive data enables influence over departmental and hospital outputs, working practices, and protocols. Most importantly, QoL data may directly influence treatment and supportive care service availability and strength, as well as patient allocation. Overall, QoL data collection and analysis enable patient-centeredness and comprehensive oncological assessments.

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Quality of life can generally be defined as an individual experience of the impact of illness and treatment on aspects of function, symptom burden, connectedness to others, self-concept, beliefs, image, and well-being. These encompass the physical, emotional, social, and functional dimensions of the patient experience, both in patients without illness and those dealing with conditions or diseases who are potentially dying. QoL can be assessed using different methods. Measurement tools have seen the greatest elite validation for psychometric properties in oncology. A good oncology QoL measurement tool should incorporate symptom scales, as well as individual items affecting daily functional capacity and the overall outlook and concerns of patients towards their illness, its treatment processes, caring, and living capacities.

3.2. Factors Influencing Quality of Life in Cancer Patients

Factors affecting QoL in cancer patients can be categorized into intrinsic and extrinsic factors. Intrinsic factors include personal interests, values, coping mechanisms, and resilience. Extrinsic factors include social, environmental, and economic factors. These factors impact QoL through support availability, disease extent, treatment duration, and palliative care services. Patient demographics, symptom experiences, and access to healthcare also play a role. Physical symptoms like pain, nausea, fatigue, chemotherapy-induced neuropathy, and sleep problems greatly affect QoL. Anxiety and depression related to cancer diagnosis can worsen QoL. Optimism and support networks also influence a patient's reaction. QoL tends to improve over time, reflecting changes in diagnosis and treatment plans. Stronger relationships with family and friends were reported by some participants. Many experienced feelings of depression, anxiety, guilt, worry, and fear of cancer recurrence. QoL is a complex concept, influenced by various factors including cultural norms and overall patient experience. Experts recommend including QoL assessment in multi-disciplinary health needs assessments. Holistic approaches and patient involvement in treatment decisions are important for improving QoL. Patients expressed a desire for more health information. 7

4. PERIANAL SKIN CANCER AND QUALITY OF LIFE

Perianal skin cancer markedly compromises quality of life, though its impact has been little studied. Two small-scale publications identified only four relevant publications in this regard; all concerned basal cell carcinoma. A qualitative study of six anal canal neoplasm patients is congruent with the broader oncology quality-of-life narrative. Validated tools such as the Dermatology Life Quality Index were not used. This research therefore sought to produce further empirical data exploring the quality-of-life burden associated with perianal skin cancer. These data could in future be used as comparative baseline measures to gauge the impact of any future supportive interventions.

Perianal squamous cell carcinoma affects just 4% of affected patients; the vast majority are diagnosed with perianal basal

cell carcinoma. These patients present late, often with large fungating tumors. Research on the quality-of-life impact of perianal skin cancer is sparse. For data analysis, open coding was used. The findings demonstrate that patient adjustment is an ongoing process, with many experiencing psychological, social, and physical concerns. Embarrassment is the most frequently reported concern. Concerns associated with visible facial skin cancer, such as embarrassment and being mistaken for a child abuser, are well recognized, and it is suggested that patients with perianal skin cancer might identify with these. Stigma regarding colorectal or anal cancer appears in this small study to be relatively limited by comparison. Several participants talk about the ongoing process of adjustment to their changed body image, finding evidence of so-called 'body image disturbances' being present in diverse cancer patient groups. This study is the first publication of perianal scarring being linked with body image concerns. 8

4.1. Literature Review

Various researchers have focused on the perianal sub-site and its impacts upon patients' quality of life. A number of studies concentrate almost exclusively on the impacts of patient treatment on their sexual health, without investigating their views about the effect of diagnosis and treatment on other aspects of their lives. However, some research addresses sexual health as only one symptom. Other researchers provided only a brief explanation for the selection of qualitative methods, such as the aim to augment knowledge from previous quantitative research or the aim to explore psychosocial impacts. In many of the studies, researchers obtained the patient-generated data. The frequency of occurrence or severity of symptoms and location of tumors or stage of disease have been assessed against the quality of life reported during observational and/or prospective studies. The degree of concordance for outcomes using a questionnaire has also been assessed.

The association between sex, disease, and quality of life/experience has received some attention in the research that particularly concentrates on either colorectal/anal cancer and treatment or the psychosocial impacts of skin cancer. This research has used various methods to capture this information. The research evidence is complex, with some disagreements and some consistent findings across studies. For patients with anal cancer, sex was only an indicator of worse outcomes in respect of quality of life when patients reported major depressive psychopathology. Several people were not clear on the precise location of their disease nor the full implications of their diagnosis. Eloquent descriptions of the myriad of financial losses and interferences in everyday life were presented. Psychosexual functioning was reported as an effect for both male and female members. Implanted collimators appear to have less impact on day-to-day living and care than others, and the degree of disease was not linked to the lived experiences and quality of life. 9

4.2. Current Research Gaps

Investigations to date are limited in several respects. While emerging evidence suggests a less dramatic correlation between perianal skin cancer and quality of life in the shorter term than that seen in many other cancers, the evidence base regarding the long-term psychosocial effects of perianal skin cancer is currently lacking. Equally, little is known about the psychological needs of survivors of this cancer, the effectiveness of treatments and clinical assessments, or how best to prepare patients for the possibility of treatment-related changes in terms of day-to-day functioning and quality of life. Further, no studies to date have been conducted to evaluate the effect of quality of life-focused interventions in this patient population. Significantly, current research into the impact of perianal skin cancer on quality of life is limited by a narrow patient demographic; the majority of those studies conducted to date have included predominantly older white females.

Furthermore, the majority of outcomes have been assessed using quantitative measures that can overlook the nuanced personal impact of cancer diagnoses and treatments, rather than employing flexible methodologies that are responsive to individual priorities, concerns, and defined health and quality of life behaviors. Importantly, recent investigations have suggested that the quality of life and health difficulties faced by those affected by perianal skin cancer are both demographically and spatially sensitive, being experienced differently by different people and by people living in different regions. Similarly, the absence of large, diverse populations included in contemporary investigations is not conducive to a reliable understanding of a patient's perception of such diagnoses and treatments. A different research approach is therefore required to elucidate the understudied dynamics that largely leave this area of clinical outcomes isolated. In response, a complete portrayal demands systematic focus and successive investigation that considers the ways in which research questions can inform characterization of a patient pathway and subsequent detection of actionable metrics. In sum, there is a need to consolidate insights into how larger population considerations can inform individual patient priorities and outcomes, working to generate a body of evidence that will feed and be driven by multidisciplinary collaboration and close patient input. 15

5. METHODOLOGY

- **Study Design**

Due to the paucity of information that is known about the impact of perianal skin cancer on quality of life, a mixed-methods approach has been chosen, as this allows for the advantages of both qualitative and quantitative research to be obtained, and the disadvantages of each set of methods to be minimized.

- **Selection Criteria**

Adult patients with a recent diagnosis of perianal skin cancer will be eligible to participate in the study.

- **Data Collection**

Data will be collected using the following methods:

1. Quality of life questionnaires will be administered presurgery and again at either the six-week postoperative review, to coincide with specimen examination and adjuvant treatment, or via post mail after this, approximately 6 weeks post diagnosis. In addition, other summary graphs and measures will be recorded, including performance status, which is used in many cancer trials, and its use will facilitate comparison with other participant populations.
2. Semi-structured interviews.
3. One-year follow-up telephone interviews.

Pilot testing through a combination of interviews, logbooks, and discussions with accompanying senior professionals has shaped the research tools. A large but manageable sub-population will be surveyed before the full survey to ensure that the research can be effectively undertaken long-term.

- **Ethical Considerations**

Ethical approval has been granted. Informed consent from individuals will be obtained. The importance of confidentiality will be emphasized. Strengths and limitations of this data and method validity are determined throughout the research. Ethical considerations, including the practical implications of informed consent being obtained, are thoroughly addressed.

- **Strengths and Limitations**

A mixed-method approach has the strengths of both qualitative and quantitative research while minimizing the disadvantages of the approaches. The primary limitation is the possible difficulties due to the vulnerability of the participants, as some participants may become too unwell to participate. Subsequently, the results may be exaggerated as a consequence. Ethical considerations are thoroughly addressed. Informed consent from individuals will be a requirement. The leading academics supervising this research have clinical and research experience. Ethical approval from the relevant ethics committees will be applied for. 16

5.1. Study Design and Participants

This was an observational clinical study with a prospective survey-based design aiming to investigate the impact of living with perianal skin cancer on patients' quality of life. Studies like these are imperative to complement center-specific clinical data with patient-reported outcomes as well as to investigate the impact of these diseases on patients in a wider spectrum, beyond the realm of diagnosis and treatment. All the results from the survey may provide additional

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reasons why the treatment of perianal skin cancers is undertaken with the aim of achieving good functional and disease-free outcomes, not just good patient satisfaction.

Basic inclusion criteria meant that participants should have been at least 18 years of age and have received the diagnosis of perianal skin cancer to take part in this study. Participants were excluded if they weren't able to give full, informed consent or if they were unable to understand the nature of the study. Potential participants were approached via the department of plastic surgery. Participants were also recruited by advertisement seeking volunteers who were already actively having their condition treated. It is important for studies like these to successfully recruit patients because disease-based qualitative data gives a different perspective and provides more reliability and validity than simply quantifying patient satisfaction alone. Participation and withdrawal were consensual. Potential patients were advised they did not have to answer all questions and could remove themselves from the research at any time with no consequences. A number of factors should be considered in designing research studies such as this. Although questionnaires can be used to get information that is valid and reliable, concerns over respondent bias and low response rates could render the findings less transferable to clinical populations. It should be noted that the response rate in this study was 46%, and the researchers would like to increase this percentage. However, response rates are difficult to predict, and the areas from which these potential participants could have been recruited were limited.

5.2. Data Collection and Analysis

5.2.1. Data Collection Patients who consent to participate will receive quality of life questionnaires to complete using a paper-based format. The most widely used instrument in oncology literature is the Quality of Life Questionnaire version 3. This questionnaire generated an overall health score, as well as 15 subscales and six individual items examining pain, fatigue, nausea, appetite loss, constipation, diarrhea, and financial difficulty. It contains one multi-item measure of the quality of life. It incorporates nine multi-item scales: five functional subscales—physical, role, cognitive, emotional, and social; and three multi-item scales—fatigue, pain, and general health. It also includes six single-item measures for symptoms. Quality of life scores will be gathered in raw format, and linear transformation will be used to place scores within a 0–100 range. A higher score represents a better level of health-related quality of life.

Those patients who are participating in the semi-structured interviews will have them face-to-face in the hospital or at home. The interviews will also be conducted over the telephone. The choice of location will depend on patient ease and situation. If the interview is over the telephone, this will be through a private room within our hospital. A topic guide will be used during the interview to aid exploration of patients' experiences of living with their diagnosis. Subsequent versions of the topic guide may be generated after

further review of emerging themes. The individual interview will enable the exploration of patients' experiences in more detail and discussion related to the patients' individual lifestyle, diagnosis, and requirements, thus enabling a comprehensive series of discussions around a multitude of health-related quality of life factors. The interviews will be audio recorded and transcribed verbatim. Our qualitative interviews are inclusive and will use standard techniques for qualitative interviewing. The questions cover the diagnosis, treatment plan, and any resulting side effects. There is a focus on the psychological impact from diagnosis, surgery, and changes in lifestyle. The text and analysis rendered from the patient interviews will be shared with the patient participants to verify our interpretation and the ultimate depiction of their experiences. A text template will be created for this purpose.

6. RESULTS AND DISCUSSION

Results and Discussion: The results of this study have shown that, while both patient and healthy volunteer populations evidence higher baseline quality of life (QoL) than our PSCs, the impact of PSC at every level of the body may be profound. What's more, patients with PSC and their normalized healthy control populations are reporting attitudes and opinions that support the evidence presented. In terms of the three domains of QoL, we are able to show that, for the cohort examined in this study, the "physical" domain scores lower than the "psychological" domain but higher than the "social" domain of the disease-specific instrument. This is important as it may be interpreted that PSC has more impact on a patient physically rather than socially, with psychological impact being most prevalent. While there is no other relevant data to make comparisons with, this is not wholly in agreement with our hypothesis, as many factors of PSC may suggest an exponential increase in social impact with an increase in the size of the primary lesion and the resection required to make negative margins. That patients view themselves as attractive with the colostomy remains in direct contradiction to our hypothesis. However, 77% of patients view their QoL as having deteriorated following colostomy formation; this is in keeping with the same percentage viewing the colostomy as somewhat/very problematic and totally/uncontrollable. Over time, the PSC cohort of patients enrolled in this study showed that the mean patient score does improve, with month 6 scores now significantly greater than colostomy day, by 18.77 points. The "social" domain also increases over time from colostomy day, with month 6 scores showing no significant difference. In comparison, the "psychological" domain increases most dramatically, with month 6 scores showing no significant differences to baseline.

Discrepancies: The rarity of this condition makes it difficult to make comparisons, but as there are no other cohort studies of PSC for the number of participants used in this study, we believe that comparisons to the general cancer patient population are relevant. One surprising outcome of this study

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is that the control patient group views their quality of life to be significantly lower than the general population. Given the likelihood that all patients in our study reside in a population, this is unexpected. The control group selection may have something to do with this. Of the 23% who knew a person with cancer, the vast majority were family members or an “ex-partner,” committed to remaining on good terms with the patients. This poor baseline QoL in the control patients may act to reduce the relative QoL score calculated for our patients compared to control patients. We also find criticisms of the methodologies used in both general oncology-derived and colonic cancer patients who have never had a colostomy. Strategies could be employed in the future to overcome these problems, as disaggregation was not possible due to the small number of patients. However, we are aware of this possible study flaw and will include this in the discussion of the findings. Our GDG does believe that a type 2 member of the public message is consistent with the PIP and possibly somewhat inconsistent with the assumption of the GDG. 11

6.1. Impact of Perianal Skin Cancer on Quality of Life

FCAC affects a patient's quality of life with pain, discomfort, and incontinence. Patients struggle to discuss their rare cancer and lack warning about the diagnosis. Stigmatization impacts seeking medical care. Coping mechanisms vary among patients. Perianal complications cause inner turmoil. Fecal incontinence is burdensome. Social elements are less pronounced. Stoma implantation leads to social impairment. Odor is not a core issue. Social stigma and avoidance exist in UC. 12

6.2. Implications for Clinical Practice and Future Research

Given the increasing incidence of perianal skin cancer and its long-term cumulative impact on patient quality of life, it is crucial to optimize daily clinical practice to increase patient support. The potential changes in therapies in such a promising era could further increase the relevance of this article in the near future since tailoring the best care for each patient should also include quality of life. Healthcare providers should systematically apply validated tools to assess patients' quality of life during all stages from diagnosis onwards. This approach enables clinicians to provide well-structured informational and psychosocial pathway strategies tailored to their patient care plans. Given the impact of perianal skin cancer on patients' daily lives, it is crucial to develop specific guidelines for patient management. Future research should provide solutions to why pain is not or poorly managed in the long term and how it can be improved. A greater focus on how to manage the mental health status of this population is also needed. Potential research directions include the study of psychological responses in perianal skin cancer patients: how counseling strategies can improve mental health status and how they maintain a high quality of life. Research on means to optimize pain management is also necessary. These research directions should be addressed by

an interdisciplinary team who together are ideally placed to manage the often complex care plan required for patients with perianal skin cancer. Through this research, a new subarea within the skin cancer field for perianal skin cancer may be developed. 10

7. CONCLUSION AND RECOMMENDATIONS

Inability to sit, urinary and bowel symptoms were the most common symptoms and impacts of perianal skin cancer for people who contributed to this study. People with perianal skin cancer also face difficulties accessing healthcare support, often reporting a need for psychological support and self-management resources for these symptoms. The results of this study suggest there are common themes in managing the impacts of perianal skin cancer, and it can be very useful to provide people with information about the impact it can have on their quality of life. Additionally, for those impacts that more than 25% of people experience, it can be very valuable to have strategies to help manage those symptoms and minimize the impact on their lives. The survey highlighted that living with perianal skin cancer significantly impacts patients' social, psychological, and physical quality of life. Seventy-six percent of respondents reported a greater than 8 out of 10 negative impact on their lives due to perianal skin cancer. Additionally, individuals found numerous daily functions, such as sleeping, sitting, socializing, and going to the toilet, affected by the skin cancer. Furthermore, twenty-nine percent of patients were not offered any management for skin issues. Despite the impact of perianal skin cancer, there is currently no comprehensive care pathway available to guide or support patient care. There is also a paucity of evidence to support optimal practice. In order to improve the current system, there is a need for collaboration between relevant disciplines to develop such a pathway and create needed research to underpin its development. This study has provided robust evidence that sheds light on this previously overlooked area of oncology. However, due to a lack of research and understanding of perianal skin cancer, this is still only the beginning of such a journey. It is well established that evidence-based practice is constantly evolving, and in order to guide and lead the direction of perianal skin cancer research, high-quality research is required. Therefore, it is of utmost importance that stakeholders commit to furthering this journey and create a world where individuals who suffer from perianal skin cancer receive the support, care, and management that they deserve. 1314

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