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*How can patient expectations
relating to skin cancer surgery be
assessed and addressed?*

Miss Katherine Farquhar

University of Glasgow

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Introduction

“Variability is the law of life, and as no two faces are the same, no two bodies are alike, and no two individuals react alike, and behave alike under the abnormal conditions which we know as disease.” William Osler¹

All living things have a tendency for variation, as indeed do our patients with their expectations. Patients’ expectations vary greatly and are moulded by factors often outwith the dermatological surgeon’s control. They may be influenced by their own or close acquaintances’ past medical procedures often providing an out-dated or exaggerated perspective. The media, online resources and social networking– however credible or dubious – are increasingly used by patients and subconsciously influence their expectations². Facebook is currently reported as the 4th most popular source of health information in the UK³.

Skin cancer surgery (SCS) is often particularly complex, involving highly aesthetic areas such as the face, where patients can constantly visualise the evolution of their treatment^{4,5}. It is therefore perhaps more vital than in other specialties that patients know what to expect from SCS. Managing patient expectations to ensure they are realistic and based on accurate information ensures that patients can be as satisfied as possible with outcomes.

Assessing expectations

Most published papers investigating patients' expectations use quantitative questionnaires⁶. Whilst useful information can easily be gathered this way, questionnaires are limited by patients' differing opinions of acceptability: an experience ranked 10/10 by one patient may be ranked much lower by another. Many qualitative components contributing to patients' feelings of satisfaction with surgery are particularly difficult to quantify and greatly variable upon an individual's perception, such as pain and scarring. Such questionnaires may be excellent for tracking one patient's expectations and how they may change over the course of treatment, but not as useful for measuring inter-patient expectations. In a systematic study of patient expectations in surgery only 17% of studies used a validated questionnaire⁶.

Patient-reported outcome measures (PROMs) are the gold standard for evaluating patient experience⁷. PROMs have been developed for other areas in dermatology such as the dermatology life quality index (DLQI)⁸, but currently there is no specific Department of Health PROM for SCS⁹. Developing a validated PROM to standardise data collection for SCS nationally would remove the questionability of the reliability, validity and precision of individual studies using invalidated methods and increase the feasibility and ease of research¹⁰.

Incorporating an evaluation of patient expectations into history taking is an easy way to ensure patients are prompted to discuss their expectations. By eliciting patients' ideas, concerns and expectations for a procedure, surgeons can gauge how realistic their expectations are. Discussing expectations as early as possible

allows for modification of overly low or high expectations, permitting the patient time to develop more realistic expectations.

Patient-centred care

The skin is a diverse organ with many functions, some more important to certain individuals than others. For the same lesion there are often numerous treatment options with different risks and benefits^{11,12}, the results more satisfactory or unsatisfactory to an individual based upon their own personal preferences.

Personalised medicine is not a new concept, and perhaps best articulated by the quote:

“The good physician treats the disease, the great physician treats the patient who has the disease” William Osler¹³.

Osler is considered a founder of modern medicine, introducing the concept that patients should be seen as individuals and not categorised by their disease. I believe this is as important for skin cancer surgeons as physicians. As Dr Osler’s quotes suggest, the high variability of our patients from their biology to psychology requires us to be adaptable if we are to satisfy them.

Involving patients in their treatment by informing them of the options and ultimately taking their preferences into consideration can help them feel in control of their health¹⁴. Thus shared decision making and taking time to ask the patient “what is important to you” can be vital in choosing between surgical

options and maintaining a high level of patient satisfaction¹⁵.

Linon et al. reported a large discrepancy between the perceptions of patients and clinicians in the treatment of non-melanotic skin cancers, including Mohs surgery and excisions¹⁶. In the same cohort 27% of patients reported complications compared to just 3% of clinicians¹⁶. Patient-centred care and better patient education could decrease such discrepancies and help surgeons meet patients' expectations.

Patient information and education

Patients are increasingly interested in their condition, and in the age of the Internet more information is available to us in our own homes than ever before².

Patients retain just 14% of verbal information accurately, so it is important to provide leaflets or websites with truthful information for later reference¹⁷.

Increasingly organisations such as the NHS and the British Association of Dermatologists have resources designed for patients, which can replace erroneous online resources^{18,19,20}. Patient decision aids have been shown to enhance patients' knowledge and improve their risk perception, allowing informed decision-making¹³. Acknowledging patient preference allows for the most appropriate treatment for the individual and their circumstances to be chosen. This minimises the number of apparently successful procedures that fail to satisfy patients¹³.

Support groups for patients

There are many patient support groups for skin cancer^{21,22}. Encouraging patients to attend and engage with others who have experienced similar procedures can alleviate their concerns about undergoing SCS²². Patient groups can give patients extended time not available in clinics and patients themselves often prefer such groups as they feel more comfortable asking questions, enabled to release their emotions, confront their fears and share experiences²². Observing other patients progress, months or even years ahead of their current prospective allows them to build up accurate expectations of what lies ahead.

Psychodermatology services and multidisciplinary teams

Skin cancers often develop on prominent places such as the centro-facial region that are highly emotive². Thus satisfaction with the cosmetic result of SCS is not only vital for the patient's wellbeing but to prevent provoking the memories and emotions of their cancer.

Recognition of the skin-brain axis clarifies the close relationship between skin disease and psychiatric disorders²³. For a subset of patients who particularly struggle psychologically with the cosmetic disfigurement resulting from difficult to manage skin cancers, expanding the availability of psychodermatology services may improve satisfaction and better meet patients' expectations.

This highlights the importance of the multidisciplinary team in caring for

patients with skin cancer. Not only are dermatologists and dermatological surgeons necessary but a larger team is often required, the input each patient requires varying upon their individual needs and circumstances. Those involved may include plastic surgeons, psychiatrists, nurse specialists and primary-care practitioners. Nurse specialists may be better placed to assess patient expectations and implement the suggested strategies such as educational means to address patient expectations than surgeons.

Advancing surgical techniques and expanding skin cancer surgery research

There are various dermatological surgery techniques developed proven to result in greater agreement between patient expectations and outcome²⁴. Such techniques include MOHS surgery, which minimises recurrence and maximises aesthetic results²⁴. However we must retain the principles of patient-centred care and not use a “one size fits all” model, which would result in sub-optimal results for some patients. Technological and technique developments can undoubtedly improve patient experience by reducing pain and improving healing. Continuation of research is thus vital to create new options for surgeons to offer patients; with more choice enabling greater personalisation of treatment.

Research into indicators that could guide margin size rather than current consensus-based margins could enable surgeons to stratify patients and inform them more accurately of the size of margins required. An example may be the

use of MITF staining in lentigo maligna where accurate interpretation of melanocyte density may allow personalisation of excisional margins rather than the current standardised 5mm margin²⁵.

There may be specific types of patients for whom we are failing to meet expectations. Research identifying such groups would allow more to be done pre-op to balance their expectations with realistic outcomes and ultimately improve patient satisfaction.

Summary

In many areas of medicine, scientific developments such as ‘stratified medicine’, tailoring treatments based on patients’ genotypes, are expected to revolutionise medicine and maximise patient outcomes²⁶. This is unlikely to ever be realistic for SCS, as there is no gene predicting which outcome parameters are of greatest importance to a specific patient and which technique will attain these best. SCS is perhaps therefore more an art than a science where surgeons’ individual experiences, strengths and weaknesses will always vary.

Although research developments are vital in advancing SCS, to best meet our patients’ expectations we need to always consider the patient as an individual and identify their personal desires for treatment. This is best done through engaging with the patient and eliciting what is important to them. We must also ensure that patients have access to appropriate “decision aids” so they are appropriately educated and informed about the options available to them. We

must then take their preferences into consideration. This is increasingly challenging when services are under growing pressure with the volume of patients requiring SCS rising.

The approaching era of personalised medicine should not only be defined by highly advanced gene-sequencing technology but also by caring clinicians who take the time to see the individual behind the skin cancer. Surgeons who do their utmost through clear communication, educational materials and patient-centred care to empower patients to have realistic expectations that they can confidently satisfy.

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