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

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Skin cancer is the most common malignancy worldwide. The incidence of NMSC is set to double in the next 30 years, with melanoma showing an equally disturbing trend [1]-[5]. Surgical intervention is required in 30% of all Dermatology referrals; commonly for skin cancer [6]. Dermatological surgery is facing increasing patient expectations and an increased requirement to meet them as part of the patient-centred paradigm. Patient expectations have been proven an important determinant of patient satisfaction [7]. Despite this, there is surprising sparse literature exploring expectations regarding skin cancer surgery [7]. This essay expands on concepts of patient expectations regarding skin cancer surgery, whilst developing strategies to assess and address them.

Rising expectations

Patient expectations of medical practice saw their first dramatic increase after the discovery of anaesthesia and anti-septics in the mid-nineteenth century [8]. Surgical advancements saw a transition from “hoping” for good health, to “demanding” good health. Patients began to “expect a technical fix for everything” with few complications (Martin. S. Pernick) [9].

We live in a revolutionary era where information once restricted to medical professionals, is now readily available to patients via various media sources. Of course, “Information is not knowledge” (Albert Einstein). Patients unfortunately have more exposure to Daily Mail articles such as “A cure for skin cancer” than reliable appropriate sources [5] [10]. The media, combined with societies emphasis on cosmetic appearance, has led to exceptionally high expectations regarding skin cancer surgery [11]. This has led to a gulf between patient hopes and the ability of dermatological services to meet them. Naturally, this is mutually frustrating for both the patient and clinician [12]. Reactions to unmet expectations range from disappointment to anger [13].

The importance of expectations

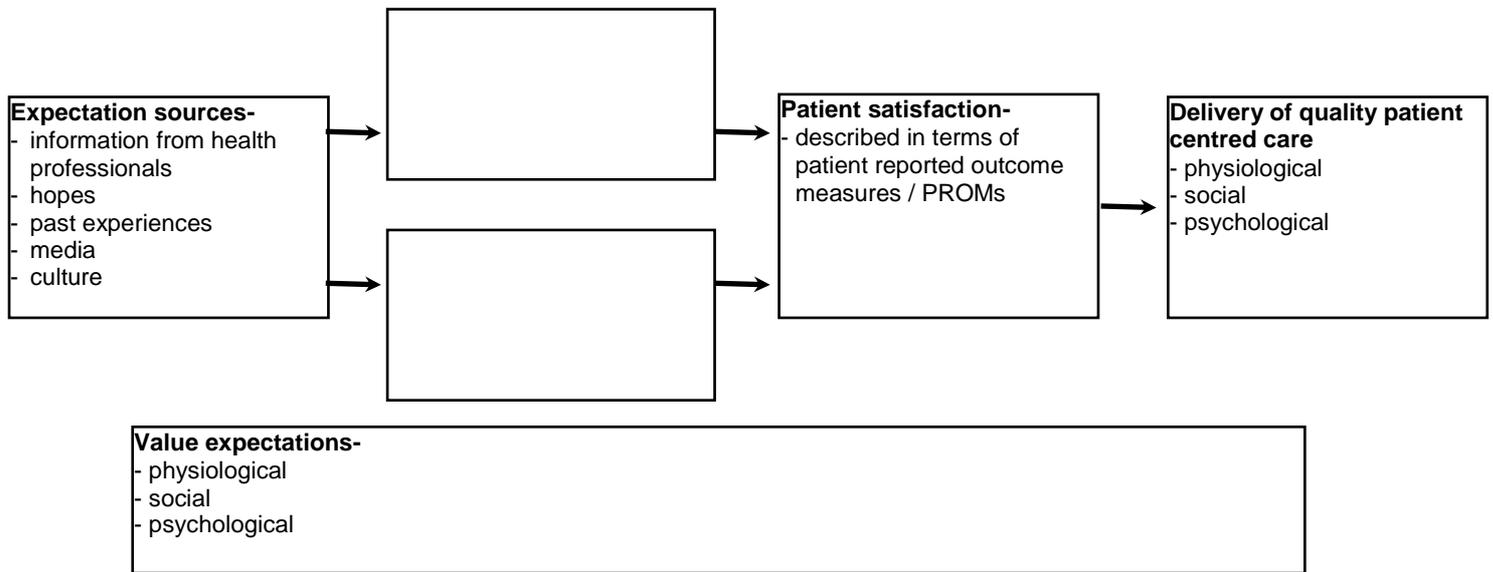
Current medical practice supports a “patient-centred paradigm” of health, described as “*a state of complete physical, mental and social well-being and not merely the absence of disease*” [14] [15]. Therefore, dermatologist reported effectiveness of skin cancer treatment is considered only part of quality care delivery. Instead, emphasis is placed on patient satisfaction which better addresses the holistic medical approach [12] [15] [16] [17]. Fulfilling the expectations of patients undergoing dermatological surgery is key to patient satisfaction; measured in terms of patient reported outcome measures / PROMs [7] [11] [18] [19]. This hierarchy is summarised in figure 1.

There is a wide bank of literature investigating patient satisfaction regarding skin surgery. However, research “upstream” into assessing and addressing patient expectations remains sparse. This is partly explained by the complex principles of expectations being poorly conceptualised [20]. Current literature demonstrates wide discrepancies in the basic definition of “patient expectations”. Bowling *et al* explored various models, eventually defining them as [20]-

“The informed prediction that given events are likely to occur during, or as a result of, health care”

This definition demonstrates “prediction expectations” rather than “value expectations” which are based on what a patient most highly “desires”. For example, a patient may *value* a complete cure for metastatic cancer highest (value expectations) but *predict* to survive a few years pain free (prediction expectations). Although “prediction expectations” are more clinically realistic, “value expectations” are an important focusing tool in deciding appropriate surgical management.

Patient expectations are unique and constructed from multiple sources including information, cultural background, beliefs, attitudes, media and family [13]. For example, older patients have higher expectations of physician friendliness, whilst females have higher expectations regarding cosmetic outcomes [15].



Asses

sing expectations

Assessing patient expectations is difficult as they are often vague, unrealistic or unknown [18]. Given the ambiguity surrounding “expectations”, it’s not surprising there’s no standardized or validated expectations assessment model for patients undergoing skin cancer surgery [7][17][20]-[22]. Current literature demonstrates the two main methods of expectation measurement are questionnaires and interviews/ consultations (table 1).

Study	Method of expectations assessment	Raised issues
Chuang GS, Leach BC, Wheless L, Lang PG, Cook J, "Preoperative expectations and values of patients undergoing Mohs micrographic surgery", <i>Dermatol Surgery</i> , Vol. 37, issue 3: 311-9, 2011 [15]	Questionnaire- - prospective pre-operative - based on analogue scale	<ul style="list-style-type: none"> - cure - specialist treatment - reconstruction only after cancer completely removed - pain control - more than a year of fellowship membership - confirmation of a cure - minimal skin removal - minimal scar
Kearney CR1, Holme SA, Burden AD, McHenry P, "Long-term patient satisfaction with cosmetic outcome of minor cutaneous surgery", <i>Australas J Dermatol</i> , Vol. 42, issue 2: 102-5, 2001 [11]	Questionnaire- - post-operative	<ul style="list-style-type: none"> - scar - cure - pain
D. Herath and R.M Emerson, "What expectations do patients have about skin surgery?", <i>British Journal of Dermatology</i> , Vol. 153, Supplement 1: 74-81, 2005 [6]	Questionnaire- - prospective pre-operative questionnaire Interview - following delivery of information leaflet	<ul style="list-style-type: none"> - scarring - loss of function (vision) - pain - return to work - infection - bruising - reassurance
S. Gossain and S. Keohane, "Patient quality of life after Mohs' micrographic surgery", <i>British Association of Dermatologists</i> , Vol. 157, supplement 1: 23-73, 2007 [23]	Interview- - Semi-structured post-operative	<ul style="list-style-type: none"> - anxiety - scar appearance and depth - embarrassment due to scar - reduced personal attractiveness - work and financial implications - social and family attitudes - physical function
K. Ahmad and B.C.P Ramsay, "Patients' fears and expectations: exploring the hidden agenda in the dermatology consultation", <i>British association of Dermatologists</i> , Vol. 159, Supplement 1: 24-69, 2008 [24]	Questionnaire- - pre-consultation	<ul style="list-style-type: none"> - treatment of skin condition - advice on skin condition - prompt diagnosis - cure
Sung Bin Cho <i>et al</i> , "Scar characteristics and treatment expectations: a survey of 589 patients", <i>Journal of cosmetic and Laser therapy</i> , Vol. 11: 224-228, 2009 [25]	Questionnaire- - pre-consultation	<ul style="list-style-type: none"> - scarring - work implications

Prediction expectations-

- physiological
- social
- psychological

Questionnaires

The development of a nationalised, standardised and reliable questionnaire exploring patient expectations would aid dermatological surgeons in assessing patient expectations individually and nationally. It would allow demographic and disease specific comparison, as well as quantitative statistical analysis of this poorly researched subject. Such a questionnaire could be developed from two sources-

- 1) Issues raised in studies exploring expectations (table 1)
- 2) Existing PROM questionnaires

Analysing expectation specific studies (table 1), the issues raised can be split into a physical psychosocial model as part of the “patient-centred paradigm” (figure 2).

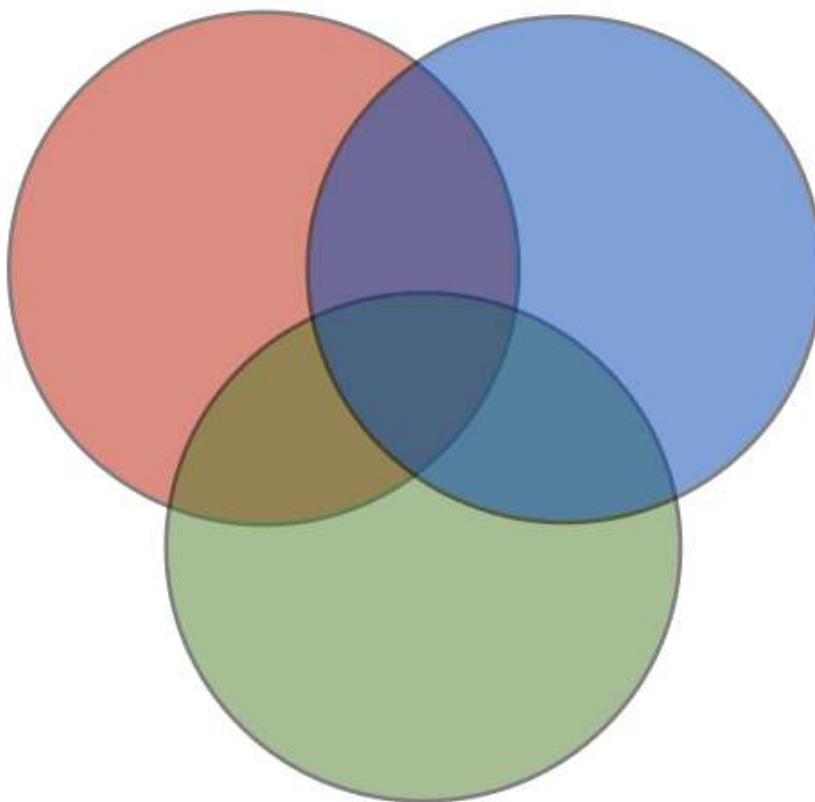


Figure 1- flow chart developed to demonstrate the important relationship between of patient expectations and patient satisfaction (PROM). Demonstrates that assessing and addressing expectations is required for delivery of quality medical care as part of

Given the important relationship between patient expectations and PROMs, and the greater quantify of PROM literature, it may be logical to expand from existing PROM questionnaires. This would allow direct comparison between domains of expectations and satisfaction. Systematic reviews of dermatological PROMs demonstrate various models (Skindex, DLQI, FSCI, POS-Head/Neck). The most appropriate potentially being the SCQOLIT questionnaire which is skin cancer specific and addresses most areas drawn from table 1 [4] [26]-[29].

In previous studies, patients have completed questionnaires at various time frames in their skin cancer management. The results demonstrate how expectations are not static [20]. Bowling *et al* emphasises the importance of questionnaires being completed at pre-consultation and post-consultation [20].

Consultations

Questionnaires and models of assessing expectations are no substitution for good verbal communication. Herath *et al* described how 12% of patients didn't read their skin cancer information leaflets meaning questionnaires can't be heavily relied on [6]. Unfortunately consultations have significant time restraints limiting the number of expectations that can be explored. Focusing on the patient centred paradigm, the most important expectations to assess are "value expectations". These will be unique and are affected by multiple factors including cancer type, lesion location, sex, past medical experiences [11] [15] [25]. Roger Neighbour, who cross examined multiple consultation models, described an "ICE" approach guide a clinicians' focus [30]-

- Ideas
- Concerns
- Expectations (as a reflection of ideas and concerns)

Addressing expectations

Addressing expectations involves modifying any unrealistic expectations and delivering appropriate care with a holistic approach [18]. General expectations of health care include being listened to, clear explanations, empathy and professionalism [13]. With medical practice now driven by evidence based guidelines, the decision on what surgery is most appropriate is, for the most part, an easy one. However, these guidelines aren't unique to individuals "value expectations". For example, despite Mohs micrographic surgery long being championed as the gold standard for NMSC of the face, certain patients mightn't be able to tolerate the long process nor be concerned about cosmetic outcome.

Ahmad *et al* demonstrated that 11% of patients attending dermatological consultations had unrealistic expectations [24]. Modifying these can be achieved through stringent communication and providing accurate understandable information. An equal understanding of the advantages of surgery and potential negative outcomes (pain, time off work, disfigurement) should be achieved. Although verbal communication is vital, patients may have difficulty retaining all information discussed during a consultation. Information leaflets, already widely used by the NHS, are an important tool to address this problem. Despite this, NICE has highlighted the need for more patient information regarding management and prognosis [31]. The use of photographs depicting anticipated scarring and potential side effects has demonstrated varying results in terms of expectation modification [32] [6].

Conclusions

The increasing incidence of skin cancer combined with rising patient expectations, makes understanding the principles of expectations important for future dermatological surgeons. Expectations affect patient satisfaction, so assessing and addressing them is a crucial part of the “patient centred paradigm”. Expectations can be assessed through questionnaires and consultations. The development of a nationalised, standardised and reliable questionnaire should be a future focus of study in this area. Addressing expectations involves modifying any unrealistically high expectations and providing the appropriate treatment based primarily on the patients “value expectations”.

Overall patient satisfaction regarding skin cancer surgery is high. Kearney *et al* demonstrated that 91% of patients were satisfied with surgery outcomes suggesting expectations are being met [11].

Rising patient expectations is considered problematic by many health care professions. However, some theorize that they are driving medical practice and research, thereby having a positive impact on the future care of skin cancer patients.

Word count- 1315 (excluding tables)

References

- [1]- T.L. Diepgen, V. Mahler, "The epidemiology of skin cancer", *British Journal of Dermatology*, Vol. 146, Supplement 61: 1–6, April 2002
- [2]- Hugh M. Gloster Jr MD^{*}, David G. Brodland MD, "The Epidemiology of Skin Cancer", *Dermatologic Surgery*, Vol. 22, issue 3: 217-226, March 1996
- [3]- Cancer research UK, 2014. [Online]. Available: <http://www.cancerresearchuk.org/cancer-info/cancerstats/types/skin/incidence/>
- [4]- Bates AS, Davis CR, Takwale A, Knevil GJ, "Patient-reported outcome measures in nonmelanoma skin cancer of the face: a systematic review" *British Journal of Dermatology*, Vol. 168, issue 6: 1187-94, June 2013
- [5]- Cancer research UK, 2014. [Online]. Available: <http://www.cancerresearchuk.org/cancer-info/cancerstats/types/skin/survival/>
- [6]- D. Herath and R.M Emerson, "What expectations do patients have about skin surgery?", *British Journal of Dermatology*, Vol. 153, Supplement 1: 74-81, 2005
- [7]- Aerlyn G. Dawn, MD, MBA, and Paul P. Lee, MD, JD, "Patient Expectations for Medical and Surgical Care: A Review of the Literature and Applications to Ophthalmology", *Survey of Ophthalmology*, Vol. 49, issue 5: 513-24, 2004
- [8]- Jacalyn Duffin, "History of Medicine: A Scandalously Short Introduction", *University of Toronto press*, pages 141-144, 1991
- [9]- Martin S Pernick, "A Calculus of Suffering: Pain, Professionalism, and Anesthesia in Nineteenth-Century America", *Columbia University Press*, pages 233-234, 1985
- [10]- Stephen Adams, "A cure for skin cancer: Doctors announce historic breakthrough as 'spectacular' drugs bring hope to thousands", September 2013
- [11]- Kearney CR1, Holme SA, Burden AD, McHenry P, "Long-term patient satisfaction with cosmetic outcome of minor cutaneous surgery", *Australas J Dermatol*, Vol. 42, issue 2: 102-5, 2001
- [12]- GMC, 2014. [Online]. Available: http://www.gmc-uk.org/patient_centred_care.pdf_25397151.pdf
- [13]- Fatimah Lateef, "Patient expectations and the paradigm shift of care in emergency medicine", *J Emerg Trauma Shock*, Vol 4, issue 3: 163-167, 2011
- [14]- WHO, 2014. [Online]. Available: <http://www.who.int/about/definition/en/print.html>
- [15]- Chuang GS, Leach BC, Wheless L, Lang PG, Cook J, "Preoperative expectations and values of patients undergoing Mohs micrographic surgery", *Dermatol Surgery*, Vol. 37, issue 3: 311-9, 2011
- [16]- Lochman JE, "Factors related to patients' satisfaction with their medical care", *J Community Health*, Vol. 9, issue 91, 1983
- [17]- Carol A. Mancuso, MD, Eduardo A. Salvati, MD, Norman A. Johanson, MD, Margaret G. E. Peterson, PhD, and Mary E. Charlson, MD, "Patients' Expectations and Satisfaction With Total Hip Arthroplasty", *The Journal of Arthroplasty*, Vol. 12, Issue. 4 1997
- [18]- Skin and Allergy News, 2014. [Online]. Available: <http://www.skinandallergynews.com/topics/dermatologic-surgery/single-article-page/follow-aidet-to-guide-patient-expectations/8a377aed905c7eeede803867f463b5ef.html>
- [19]- Renzi, C., Abeni, D., Picardi, A., Agostini, E., Melchi, C.F., Pasquini, P., Puddu, P and Braga, M, "Factors associated with patient satisfaction with care among dermatological outpatients", *British Journal of Dermatology*, Vol.145: 617–623, 2001

- [20]- Bowling A, Rowe G, Lambert N, Waddington M, Mahtani KR, Kenten C, "The measurement of patients' expectations for health care: a review and psychometric testing of a measure of patients' expectations", *Health Technol Assess*, Vol. 16, issue 30, 2012
- [21]- Mitchell Peck *et al*, "Measuring Patient Expectations Does the Instrument Affect Satisfaction or Expectations?", *Medical Care*, Vol. 39, issue 1: 100–108, 2001
- [22]- Fiona Bath-Hextall, Claire Jenkinson, Arun Kumar, Jo Leonardi-Bee, William Perkins, Karen Cox , "Longitudinal, Mixed Method Study to Look at the Experiences and Knowledge of Non Melanoma Skin Cancer From Diagnosis to One Year", *BMC Dermatol*, Vol. 13, issue 13: 13, 2013
- [23]- S. Gossain and S. Keohane, "Patient quality of life after Mohs' micrographic surgery", *British Association of Dermatologists*, Vol. 157, supplement 1: 23-73, 2007
- [24]- K. Ahmad and B.C.P Ramsay, "Patients' fears and expectations: exploring the hidden agenda in the dermatology consultation", *British association of Dermatologists*, Vol. 159, Supplement 1: 24-69, 2008
- [25]- Sung Bin Cho *et al*, "Scar characteristics and treatment expectations: a survey of 589 patients", *Journal of cosmetic and Laser therapy*, Vol. 11: 224-228, 2009
- [26]- Lee EH *et al*, "A systematic review of patient-reported outcome instruments of nonmelanoma skin cancer in the dermatologic population", *J Am Acad Dermatol*, Vol. 69 issue 2: 59-67, 2013
- [27]- John S. Rhee, MD, MPH, B. Alex Matthews, PhD, Marcy Neuburg, MD, Brent R. Logan, PhD, Mary Burzynski, RN, and Ann B. Nattinger, MD, MPH, "The Skin Cancer Index: Clinical Responsiveness and Predictors of Quality of Life", *Laryngoscope*, Vol. 117, issue 3: 339-405, 2007
- [28]- D. Burdon-Jones, K. Gibbons, "The Skin Cancer Quality of Life Impact Tool (SCQOLIT): a validated health-related quality of life questionnaire for non-metastatic skin cancers", *J Eur Acad Dermatol Venereol*, Vol. 27, issue 9: 1109-1113, 2013
- [29]- S.J. Cano *et al*, "The Patient Outcomes of Surgery—Head/Neck (POS-Head/Neck): A new patient-based outcome measure", *J Plast Reconstr Aesthet Surg*. Vol. 59, issue 1:65-73, 2006
- [30]- Roger Neighbour, "The inner consultation", *Radcliffe Publishing*, 2005
- [31]- Julia Verne, "Improving Outcomes for People with Skin Tumours including Melanoma", *National Institute for Health and Clinical Excellence*, 2010
- [32]- Cassileth BR *et al*, "The use of photographs of postoperative results prior to melanoma resection", *Plast Reconstr Surg*, Vol. 74, issue 3: 380-384, 1984