

Research letter

Quantitative survey into value clarification of discussed treatment options among patients treated for basal cell carcinoma

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DEAR EDITOR, There are many effective treatment options for basal cell carcinoma (BCC).¹ To ensure a shared treatment decision, it is essential to understand patient preferences, values and experience with treatments.² We evaluated patients' recollections of the treatment choices for their BCC and what kind of information they valued most by doing a quantitative survey via the largest Dutch patient federation ('Patiëntenfederatie Nederland', PFN). The PFN includes a 25 000-member patient panel; their medical history is not reported. A survey was developed by the Dermatology Department of the Maastricht University Medical Center+ in collaboration with patients with BCC and PFN employees and was sent out to the panel by e-mail. Patients who recalled ever having a BCC answered the call and were sent a second e-mail which included a link to the online survey. The survey covered patient and tumour

characteristics, treatment setting, treatment options discussed, and the need for additional information and support. Responders were shown several statements related to making treatment decisions and were asked to state their importance on a 10-point Likert scale and prioritize them.

Three hundred and nine responders participated; 55% were aged 50–70 years, 58% were highly educated and 46% had a BCC 1–5 years ago. Most respondents were treated in general hospitals (62%) by dermatologists (61%). Thirty-eight per cent of the patients were treated by nondermatologists (plastic surgeons and surgeons). Overall, 55% reported that only one treatment option was discussed. Surgical excision (71%) was mentioned most often, followed by Mohs micrographic surgery (20%), imiquimod (15%), 5-fluorouracil (23%), photodynamic therapy (19%), radiation therapy (4%), cryotherapy (34%) and other options (7%), such as 'laser' and 'unknown cream'. No participants recalled being offered the option 'no treatment', despite growing data suggesting that this may be appropriate in specific situations.³ Some patients would have liked additional information on diagnosis (25%) and treatment options (28%). Figure 1 shows the type of information patients

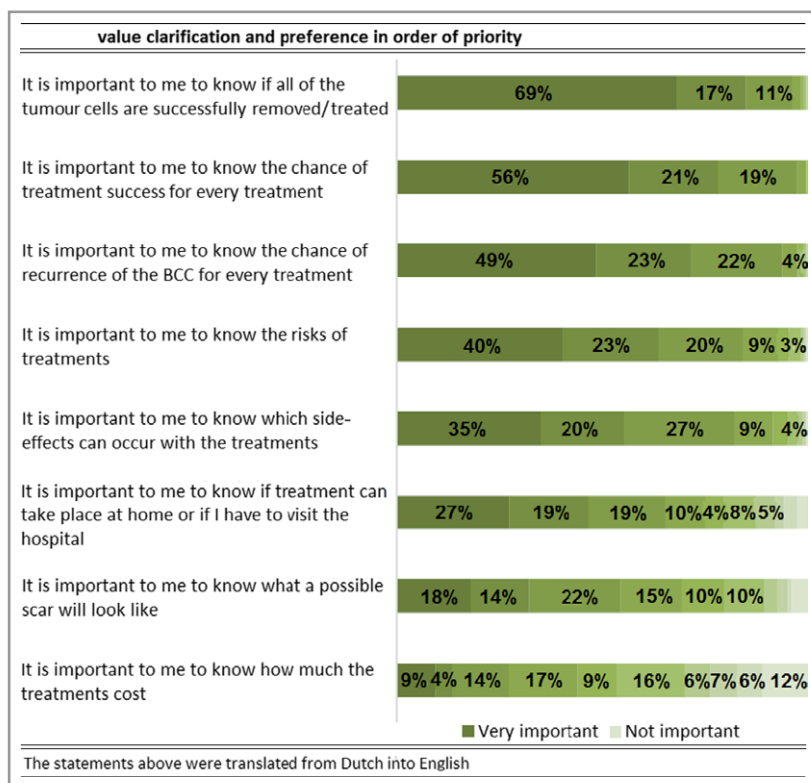


Fig 1. Value clarification and patient preference in order of priority. BCC, basal cell carcinoma

valued, in order of priority. Overall, 69% of responders indicated that it was essential to know if the entire BCC was successfully removed. Information about the chance of treatment success for each therapy was also considered important. Furthermore, knowing about risks and side-effects was important. Information about treatment logistics (in-hospital or at-home) was lower in order of priority (27%), as was the cosmetic result (18%).

Overall, 55% of the patients reported that they were presented with only one treatment option and 25–28% felt a need for additional information. For low-risk BCCs, treatment options are surgical excision or noninvasive modalities like imiquimod, 5-fluorouracil, photodynamic therapy, and electrodesiccation and curettage; for (facial) high-risk BCC options are surgical excision, Mohs micrographic surgery or radiation therapy.¹ The fact that, often, only one treatment option was discussed suggests that shared decision-making is not incorporated in current practice. Discussing all therapeutic options is important in situations where individual patient preferences may vary, and clinical outcomes are similar.^{4,5}

A recently published focus group study of patients with BCC indicated a need for tailored information and involvement in the decision-making process.⁶ This survey confirms that patients value receiving specific information like treatment success, chance of recurrence, side-effects and logistics for different treatments.

A limitation of this study design is potential recall bias. We could not verify if patients correctly remembered having had a BCC or the information on treatment options they were provided with. However, it still seems informative to assess patients' values and needs for information long term, after the worry of diagnosis and treatment has faded. The relatively young mean panel age (62 years) could be an explanation for the low number of patients with a history of BCC, although nonresponsiveness and selection bias are also likely. Also, we did not include treatment recovery time in the survey.

In conclusion, our study suggests that often, patients with BCC are not given sufficient information on all treatment options. This study also suggests that patients would like more information on treatment efficacy, risks and side-effects of the possible treatments. We need tools to help physicians and patients with shared decision-making in order to ensure that patients receive optimal care that matches their clinical situation, values and preferences.

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