The use of semistructured interviews to assess quality of life impacts for patients with uveal melanoma

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ABSTRACT ●

Objective: There are limited studies on uveal melanoma and patient quality of life. However, the burden of implementing a patient-reported outcome measure to collect this information in a clinical setting is unknown. The objectives of this study were (*i*) to understand the issues of quality of life that are most important to patients undergoing treatment for uveal melanoma, (*ii*) to explore patient views on the European Organization for Research and Treatment of Cancer's (EORTC) ophthalmic oncology quality of life questionnaire (QLQ-OPT30), and (*iii*) to assess patient willingness to complete questionnaires measuring quality of life on an ongoing basis.

Design: This was a qualitative study.

Participants: The study included 10 patients treated for uveal melanoma with brachytherapy at the Alberta Ocular Brachytherapy Program, with a mean follow-up period of 16.3 months (range 5–33 months) after diagnosis.

Methods: The participants completed a qualitative interview over the phone with a trained interviewer between November 2014 and January 2015. Participants completed the QLQ-OPT30 according to their current symptoms and then elaborated on their responses. The participants then completed a semistructured interview to provide more information about the symptoms or issues that had the most impact on quality of life.

Results: The participants expressed positive feelings about the QLQ-OPT30; however, the participants' responses revealed that several themes, including mental health, impact of diagnosis and treatment on family, travel and financial burdens of treatment, and impact on work and home life, were missing in the questionnaire.

Conclusions: The QLQ-OPT30 performed well, but some missing constructs were identified. Furthermore, participants took 23 minutes to complete the QLQ-OPT30 with a trained interviewer, and this could present logistical challenges when using it at the point of care.

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Uveal melanoma is the most common primary intraocular cancer in adults, but it is rare compared with other types of cancer, with an incidence rate of only 5.1 cases per million people.[1] Until recently, enucleation, or removal of the eye, was the most common treatment. Advances in radiation and surgical techniques have given rise to eye-sparing options, and brachytherapy has emerged as one of the most common treatments for tumours worldwide. With brachytherapy, a radioactive plaque is surgically placed behind the patient's eye, remains there for several days (5–7 days in the case of E.W.'s practice), and then is removed. Brachytherapy has several advantages over enucleation. Preserving the eye is typically aesthetically superior to enucleation and is less emotionally distressing to patients, and useful vision from that eye may be retained in the majority of patients, with no decrease in overall survival.[2]

Brachytherapy is associated with more medical visits and interventions preoperatively and postoperatively compared with enucleation. Patients may experience changes in their visual acuity, pain, and distress because of risk of recurrence,[3] all of which can have a negative effect on patients' quality of life. By measuring and tracking these experiences, clinicians can be more informed about patient care, which, ultimately, may improve the patient-centredness with which this care is delivered.

Patient-reported outcomes (PROs), such as quality of life, are increasingly used to measure patients' well-being and the symptoms they are experiencing.[4] PROs are standardized questionnaires that ask patients about symptom severity, physical function, and ability to carry out daily activities.[5] There are many methods of collecting PROs; collection of data during regularly scheduled visits is commonly referred to as a "point-of-care" evaluation.[6] There are unique considerations when selecting a PRO questionnaire for use at the point of care rather than in a clinical trial. Questionnaires that are too long have been shown to have lower completion rates and affect the validity of responses.[6] It should be easy to score the questionnaires quickly so that the results inform communication with patients without affecting clinical workflow.[7]

Specific to oncologic care, PROs offer several advantages when collected at the point of care, including improved communication between physician and patient; improved health-related quality of life and emotional functioning;[7] and improved symptom management,[8] such

http://dx.doi.org/10.1016/j.jcjo.2016.10.005
ISSN 0008-4182/16

Canadian Ophthalmological Society | Société canadienne d'ophtalmologie
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as referrals to psychosocial care[9,10] or pain management.[11] Patients with cancer may benefit from the use of PROs because of their considerable levels of physical and psychosocial distress.[12,13]

The most relevant PRO questionnaire available for patients diagnosed with uveal melanoma is the 30-item QLQ-OPT30, developed by the European Organisation for Research and Treatment of Cancer (EORTC) Ophthalmic Oncology Task Force.[14] As with all EORTC tumour-specific questionnaires, the QLQ-OPT30 is designed to be used with another 30-item questionnaire, referred to as the QLQ-C30, which is generic to all cancer diagnoses.[15]

There are, however, some limitations to using the QLQ-OPT30 at the point of care. First, when combined with the QLQ-C30, there are 60 items in total, and thus the questionnaire may be too long to administer in a clinical setting. Second, feedback from patients in a Polish validation study raised questions about the appropriateness of the QLQ-OPT30 when used with some patients.[16] Third, patients with uveal melanoma rarely report symptoms such as constipation, diarrhea, appetite loss, nausea, or vomiting,[17] and questions on these symptoms constitute the bulk of items in the QLQ-C30. This may reduce the sensitivity of both questionnaires for patients with uveal melanoma, making it difficult to discriminate between patients who report no or few problems with these symptoms.[6]

As a result of these concerns, this exploratory study set out to address four aims: (*i*) to understand the issues of quality of life that are most important to patients undergoing brachytherapy for uveal melanoma, (*ii*) to explore patient views on the QLQ-OPT30 questionnaire, (*iii*) to assess the length of time to complete the QLQ-OPT30, and (*iv*) to assess patients' willingness to complete the questionnaires measuring quality of life on an ongoing basis. We chose to use only the QLQ-OPT30, rather than the QLQ-C30 plus the QLQ-OPT30, for two reasons: (*i*) the finding by the Polish validation study that many of the items in the QLQ-C30 did not apply; and (*ii*) guidance from the International Society for Quality of Life Research that recommended questionnaires intended for use at the point of care be brief.[18]

Methods

Study population and setting

Participants were recruited from the Alberta Ocular Brachytherapy Program at the Royal Alexandra Hospital in Edmonton, Alberta, and the Rockyview Hospital in Calgary, Alberta. All participants had received treatment for uveal melanoma at clinics located in Edmonton or Calgary. Ethical approval for the study was provided by the Health Research Ethics Board of Alberta.

Sampling

A series of consecutive patients, over 18 years of age, whose first language was English and who had been treated for uveal melanoma in the past 3 years, were invited to enroll in the study. The list included patients of both genders and of different ages, who were living at different distances from a clinic location and had varying levels of social and financial support.

Interview procedure

A trained interviewer (B.K.) made 3 attempts to reach each patient by phone to set up an interview. Those who agreed to participate underwent a 2-step interview that was scheduled at a time convenient for the participant.

Participants were asked to complete the QLQ-OPT30 (following developer instructions and using the 1-week recall time frame) and provide answers based on their current symptoms. Questions in the QLQ-OPT30 were grouped by category: ocular irritation (items 31–36); vision impairment (items 37–39); headaches (item 40); worry about disease recurrence (items 41–43); issues related to appearance (items 44–45); functional problems caused by vision impairment (items 46–51); problems with activities and reading (items 51–52); functional problems in the treated eye (items 53–58); and difficulty driving (items 59–60). Response options ranged from "not at all" (score of 1) to "very much" (score of 4). A total score was generated by summing the responses to all the questions, with a minimum score of 30 and maximum score of 120; higher scores indicated greater symptom severity.

Follow-up questions were asked after completion of each category. For example, after the 6 questions on ocular irritation, the interviewer asked the patient, "Did you experience other types of irritation in your treated eye?" to determine if the questions on ocular irritation encompassed the experiences of the patient. The interviewer then asked the patient, "How much would you say the irritation in your treated eye impacts your quality of life?" These questions, or variants based on the content and previous answers of the patient, were asked for each section.

The second step of the interview process involved a semistructured interview, which the interviewer completed immediately after administration of the QLQ-OPT30. In the semistructured interview, the interviewer used a predefined list, or guide, of questions. The guide was followed, but the interviewer asked follow-up questions of the respondent to gather more information or to follow the natural trajectory of the conversation. All comments were recorded by the interviewer in detailed notes.

Analysis

Because of the exploratory nature of this study, an inductive analysis approach was undertaken. A thematic content analysis of the patient responses from all components of the interview was conducted. This type of analysis is sufficient for projects that are exploratory in nature or when the goal is to identify key issues of concern for a patient population.[19] The interview transcripts were