ORIGINAL ARTICLE

Breaking down barriers to communicating complex retinoblastoma information: can graphics be the solution?

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ABSTRACT ● RÉSUMÉ

Objective: To investigate the impact of a graphical timeline summarizing bilateral retinoblastoma disease and treatment outcomes on parents' understanding of complex medical information.

Design: Cross-sectional survey.

Participants: Parents of children with retinoblastoma who were being actively managed at The Hospital for Sick Children were recruited. Forty-five parents from 42 families participated.

Methods: After a standardized presentation on retinoblastoma and visual tool named Disease-Specific electronic Patient Illustrated Clinical Timeline (DePICT), parents completed a 19-item questionnaire designed to assess their understanding of treatment choices for 2 eyes in bilateral retinoblastoma as communicated using DePICT. SPSS was used to perform statistical analysis.

Results: Forty-five parents from 42 families participated (65% female). Median age of participants was 34 years. Median level of participant education was completion of college/trade school. The median level of annual income was $40 000 to $70 000 CDN. Median time since diagnosis of retinoblastoma in their child was 13.5 months. Twenty-three (51%) participants were parents of children with unilateral retinoblastoma, and 22 (49%) were parents of children with bilateral retinoblastoma. Median number of correct answers was 15 of 19, and mean score was 77%. Normal distribution of scores was noted. English as a first language was significantly associated with score ($p = 0.01$). No significant association was observed between other variables and score in all analyses.

Conclusions: This study builds on the validation of DePICT by demonstrating that parents can achieve good comprehension even when considering choices for treatment for 2 eyes with bilateral retinoblastoma. Clinical application of this tool can enhance the consent process.

Objet : Étudier l'impact d'un graphique chronologique résumant l'évolution et les résultats du traitement d'un rétinoblastome bilatéral sur la compréhension par des parents d'informations médicales complexes.

Nature : Étude transversale.

Méthodes : On a recruté des parents d'enfants atteints d'un rétinoblastome qui étaient activement pris en charge au Hospital for Sick Children. Après une présentation normalisée du rétinoblastome et d'un outil visuel nommé Disease-Specific electronic Patient Illustrated Clinical Timeline (DePICT), les parents ont rempli un questionnaire de 19 questions conçu pour évaluer leur compréhension des options de traitement pour deux yeux, dans les cas de rétinoblastome bilatéral, telles qu'expliquées dans l'outil DePICT. Le logiciel SPSS a été utilisé pour l'analyse statistique.

Résultats : 45 parents de 42 familles ont participé à l'étude (65 % de femmes). L'âge médian des participants était de 34 ans. Le degré médian d'instruction des participants correspondait à un diplôme d'études collégiales ou d'études professionnelles. La tranche médiane de revenu annuel était de 40 000 $ à 70 000 $ CA. Le temps médian écoulé depuis le diagnostic du rétinoblastome de l'enfant était de 13,5 mois. En tout, 23 participants (51 %) avaient un enfant atteint d'un rétinoblastome unilatéral et 22 (49 %) avaient un enfant atteint d'un rétinoblastome bilatéral. Le nombre médian de réponses exactes était de 15/19, et le score moyen était de 77 %. La distribution gaussienne des scores a été notée. L'anglais comme langue maternelle était significativement associé au score (p = 0,01). Aucune association significative n'a été observée entre les autres variables et les scores, dans l'ensemble des analyses.

Conclusions : Cette étude renforce la validation de l'outil DePICT en démontrant que des parents peuvent acquérir une bonne compréhension même lorsqu'ils doivent évaluer des options de traitement pour deux yeux, dans les cas de rétinoblastome bilatéral. L'application clinique de cet outil peut améliorer le processus de consentement.

Retinoblastoma is a pediatric cancer of the retina that has the devastating consequences of blindness and death. It can affect 1 eye (unilateral) or both eyes (bilateral).[1] Because retinoblastoma is a pediatric disease, parents and caregivers are placed in the role of the primary decision-maker.[2] Optimal management of retinoblastoma is multidisciplinary and involves pediatric ophthalmologists, pediatric oncologists, ocular pathologists, social workers,

geneticists, and ophthalmic imaging technicians.[3] Treatment is also multimodal, dependent on the clinical characteristics at presentation, and includes options such as enucleation, systemic chemotherapy with focal laser and cryotherapy, local chemotherapy that is administered periocularly or through the ophthalmic artery, and radiation therapy.[3] Furthermore, in bilateral retinoblastoma, parents are required to consider the status of 2 affected eyes at once in treatment choices.

Studies suggest that complicated medical information is often delivered in fragments under the constraints of the realities in clinical practice,[4] and that health materials such as consent forms and patient educational materials fail to provide suitable information for decision-makers.[5] These factors compromise understanding of treatment and outcomes, and interfere with optimal delivery of treatment.[5] On the contrary, decision aids provide tailored information specific to helping people make choices, and a Cochrane review has shown that they can improve knowledge about clinical options, increase participation in the decision-making process, and lead to better understanding of treatment outcomes.[6]

Currently, more than 320 decision aids are registered in the Cochrane Decision Aids Library Inventory.[7] Research suggests that graphs are optimal aids in health-related communication with individuals having low education attainment, but none of these decision aids exists for retinoblastoma.[8–10]

Therefore, our group developed a visual tool named Disease-specific electronic Patient Illustrated Clinical Timelines (DePICT) that summarizes treatment histories of patients with retinoblastoma for clinicians to access point-of-care information and has been validated among parents in a previous study.[11] The study demonstrated that parents of patients with retinoblastoma were able to interpret timelines for treatment of 1 eye with retinoblastoma achieving a mean comprehension score of 86%. However, the study did not distinguish between unilateral and bilateral disease, and evaluated understanding of treatment choices pertaining to 1 eye instead of 2 eyes at once. The primary purpose of this study is to determine whether the DePICT decision aid is also effective in communicating the complexity of bilateral disease where treatment is specific for each eye while also taking into consideration the status of the other eye to ensure the best visual outcome for the child. The secondary purpose of the study is to determine whether demographic factors affect comprehension.

METHODS

A cross-sectional observational study was conducted. Parents of children with the diagnosis of retinoblastoma were recruited from January through August 2009 at an urban quaternary care pediatric hospital in Canada. This project was approved by the Hospital for Sick Children's institutional review board.

Development of materials

Eight DePICT cards were developed by extracting deidentified treatment timelines of bilateral disease from a retinoblastoma database (eCancerCare^retinoblastoma). The timelines were grouped into cards (Fig. 1) based on the severity of disease at the time of diagnosis according the International Intraocular Retinoblastoma Classification ranging from group A to E, where group A is least severe and group E is most severe intraocular disease.[12] The timelines of groups B, C, and D were divided into "best" and "worst" categories to simulate real-life complexity of treating 2 eyes in 1 patient. The best category refers to the eye with a less severe grouping (i.e., group B eye compared with group C eye of the same patient), whereas the worst category refers to the eye with a more severe grouping (i.e., group C eye compared with group B eye of the same patient). A legend for the cards was provided (Fig. 2).

A 19-item questionnaire with a predetermined template of correct answers validated by retinoblastoma experts was constructed to evaluate parents' comprehension of the treatment of bilateral retinoblastoma (Fig. 3).

Selection and recruitment of study population

Parents of children with retinoblastoma were identified as potential participants and received a letter of information to introduce the study. A week before the interview, parents were contacted by telephone by one of the authors (H.H.C.) to establish initial contact and to confirm interest. Parents were approached at their appointments, and written consent was obtained if parents were interested in participating. Fifty-one parents were invited to participate and the final sample consisted of 45 participants.

Administration of questionnaires

Parents were given a 10-minute standardized explanation of the DePICT cards by a single researcher (H.H.C.), after which they were asked to complete the 19-item questionnaire using the DePICT cards. Time to complete questionnaire was not included because it was impractical in a clinical setting with multiple interruptions.

Sample size and data analyses

Based on our previous study demonstrating a mean comprehension score of 86% (95% confidence interval [CI] 81.3–90.6),[11] it was estimated that with increased complexity of the design the mean comprehension score would be 80%. A sample size of 39 patients completing the task would provide a power of 0.80 and 95% CI.[13]

Statistical analysis was performed using SPSS. Ten independent variables were analyzed in the study: six interval-level variables (age, familiarity with retinoblastoma, time since diagnosis, income, level of ease with understanding and following DePICT, and level of DePICT recommendation to newly diagnosed families) and 4 categorical variable (sex, presence of bilateral disease, educational status, and English as a first language).