Est-ce qu’une approche de groupe faciliterait l’acceptation de la canne chez les personnes ayant un syndrome d’Usher?

Document-synthèse de veille informationnelle

Recherche documentaire
Francine Baril, technicienne de documentation
Josée Duquette, agente de planification, programmation et recherche

Préparation du document
Josée Duquette, agente de planification, programmation et recherche

Le 9 juin 2008
Est-ce qu’une approche de groupe faciliterait l’acceptation de la canne chez les personnes ayant un syndrome d’Usher?

Contexte de la demande
Il est fréquent que les personnes ayant un syndrome d’Usher ou une rétinite pigmentaire aient de la difficulté à accepter d’utiliser une canne blanche dans leurs déplacements, principalement en raison de son caractère symbolique. De ce fait, ils ne recourent que tardivement aux services en O&M pour apprendre les techniques d’utilisation de la canne. Pourtant, une utilisation plus précoce de la canne leur serait davantage bénéfique. Les cliniciens du programme Surdicécité désirent donc savoir si une approche de groupe faciliterait l’acceptation de la canne chez les personnes ayant un syndrome d’Usher et les amènerait de ce fait à l’utiliser de façon moins tardive.

Nous avons vérifié dans la littérature s’il existe des informations sur l’impact du recours à une intervention de groupe sur l’acceptation de l’utilisation de la canne chez les personnes ayant un syndrome d’Usher ou une rétinite pigmentaire.

Note : Les cliniciens du programme Surdicécité ne désirent pas avoir de sommaire ni de sommaire exécutif se rapportant à un nombre limité de documents tel qu’il est proposé dans le plan d’action prévu pour la Veille informationnelle. Ils préfèrent recevoir plutôt une liste des articles et documents trouvés ainsi que leur résumé, dans leur langue originale.

Sommaire

Aucun article se rapportant spécifiquement à cette question n’a été répertorié. Par contre, étant donné que l’acceptation de l’utilisation de la canne par l’usager ayant un syndrome d’Usher dépend entre autres de son stade d’ajustement psychologique à sa maladie, des articles traitant des phases d’ajustement à la rétinite pigmentaire ont été relevés (Siple Milles, 2004; Hayeems, Geller et al., 2005). Il est par ailleurs reconnu que sans les ressources et services professionnels, l’intensité et la durée de la phase d'ajustement s’intensifient; une intervention professionnelle précoce peut donc aider l’usager dans son cheminement d’ajustement et l’amener plus rapidement à accepter l’utilisation de la canne blanche.

Par ailleurs, Haymes et al. (1996) ont étudié l’influence de la vision et des variables psychologiques sur la mobilité des personnes avec une rétinite pigmentaire tandis que Higgerty & Williams (2005) ont décrit un groupe d’entraînement à la mobilité.

**Background:** People with retinitis pigmentosa (RP) experience functional and psychological challenges as they adjust to progressive loss of visual function. The authors aimed to understand better the process of adjusting to RP in light of the emotional suffering associated with this process. **Methods:** Adults with RP were recruited from the Foundation Fighting Blindness and the Wilmer Eye Institute in Baltimore. Focus groups and semistructured interviews addressed the process of adjusting to RP and were audiorecorded and transcribed. The transcripts were analysed qualitatively in order to generate a model of adjustment. **Results:** A total of 43 individuals participated. It was found that, on diagnosis, people with RP seek to understand its meaning in their lives. Mastering the progressive functional implications associated with RP is contingent upon shifting personal identity from a sighted to a visually impaired person. In this sample, six participants self identified as sighted, 10 self identified as in transition, and 27 self identified as visually impaired. This adjustment process can be understood in terms of a five stage model of behaviour change. **Conclusions:** The proposed model presents one way to understand the process of adjusting to RP and could assist ophthalmologists in meeting their moral obligation to lessen patients' suffering, which arises in the course of their adjustment to progressive loss of visual function.


We investigated the mobility performance of subjects with retinitis pigmentosa (RP) as a function of clinical measures of residual vision and psychological variables. We found a highly significant correlation between clinical measures of residual vision and mobility. Pelli-Robson contrast sensitivity and residual visual field together explained 64% of the variance in mobility performance in an indoor shopping mall. We suggest a simple new clinical method of scoring the visual field for predicting mobility performance, the RP Concentric Field Rating. The RP Concentric Field Rating alone explained 60% of the variance in mobility performance. In spite of expectations derived from reading the recent literature, we did not find a significant correlation between psychological variables and mobility performance in a group of subjects with RP.

This article describes a group training program for sighted trainee orientation and mobility (O&M) instructors in South Africa, where the need for O&M instructors is great and the availability of services is limited. The outcome was positive and encouraging and provides the initiative for the findings to be more broadly applied and for further study of the application with clients.


Moos and Schaefer's (1993) integrated coping model and Prochaska and DiClementi's (1982) Transtheoretical Model of Change (TMC) were utilized to evaluate coping responses of individuals with retinitis pigmentosa (RP). One hundred twenty-five adult volunteers with RP completed the Coping Responses Inventory (CRI-A), the Biehl Sensory Loss Scale (BSLS), and a Transtheoretical Model of Change questionnaire. The CRI-A was used to measure reliance on approach, avoidance, behavioral, and cognitive coping responses. The BSLS provided a measure of adjustment for individuals with RP. A brief questionnaire based on the TMC was used to identify stage of change (i.e. precontemplation, contemplation, preparation, action, maintenance) for each participant. As predicted, participants relied on approach-focused strategies more in the latter TMC stages, but maintained avoidance-focused responses throughout all stages of behavior change. Generally, cognitive responses were used throughout the five TMC stages with a significant reduction during the maintenance stage, while behavioral scores increased significantly after the contemplation stage. Findings generally confirmed the third hypothesis that persons with RP in the early and late stages of behavior change have higher adjustment scores than those at the intermediate stages. Moreover, there was no evidence of a positive relationship between reliance on avoidance responses and successful adjustment, regardless of whether BSLS scores or self-reported "walk" scores were used as measures of personal adjustment success for individuals with RP. When BSLS scores were used to index adjustment, there was a significant inverse relationship between avoidance score and adjustment score. Likewise, the prediction that a positive relationship exists between reliance on approach strategies and adjustment success for individuals with RP was not confirmed. Finally, the frequency of individuals with RP across the five TMC stages closely matched empirical data generated from other applications of the TMC model. The application of the TMC model to the process of adjusting with RP was validated. Examination of these findings indicated that while avoidance coping may not contribute to immediate adjustment, it is apparently an important component of the process that leads to successful adjusting to RP.