

## ABSTRACT

An investigation into the knowledge base and attitudes toward albinism among a sample of Barbadian and Trinidadian nationals

The purpose of this study was to identify the knowledge base of and the attitudes toward albinism among a sample of Barbadian and Trinidadian nationals and to ascertain the quality of life of eight persons living with albinism.

The first sub-sample of 177 persons consisted of 63 males and 114 females, in the following age ranges: 10-30 (n= 48); 31-50 (n= 75); and 50-75 (n= 54) completed the Knowledge Base of Albinism Questionnaire (KBAQ) and interviews. The second sub-sample of 300 nationals of Barbados and Trinidad consisted of 100 males and 200 females in the 10-30 (n=141); 31-50 (n=97); and 50-75 (N=62) age ranges completed the Attitude and Behaviour Questionnaire towards persons with Albinism (ABAQ). Eight persons with albinism completed the Medical Outcomes Surveys (MOS) using a case study methodological approach to provide a real-life perspective of living with albinism.

In chapter five, section one factor analysis revealed the factor structure of the Attitudes and Behaviours toward Albinism Questionnaire. The factors of misconception, sympathy, and empathy were identified and the data analysed to assess attitudes toward persons with albinism. In section two, the data were analysed to ascertain the knowledge base of the persons about albinism. The age and sex categories were analysed to determine any significant differences. In section three, the qualitative analyses of the case studies profiled the quality of life of eight persons with albinism.

The findings suggest that there was positive regard for persons with albinism. Most of the persons with albinism had no knowledge of the Hermansky Pudlak Syndrome and disliked the stigmatisation, the isolation and the name-calling. The majority of professionals knew that persons with albinism had normal intelligence. The eight persons with albinism indicated that their inability to acquire a driver's licence was their greatest setback but they enjoyed a reasonable quality of life. Recommendations emanating from the research were advanced.

**Keywords:** Albinism; Hermansky Pudlak Syndrome; Jennifer Deanne Ford; attitudes; knowledge base; quality of life