Pains among persons with albinism in Malaysia: A call for immediate interventions

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Abstract

Being part of Malaysia’s human resource persons with albinism (PWA) deserve attention. They are visually impaired, craning their neck and bending their body in order to read and perform other tasks that leads to pain. Pains are associated with school functioning deficiencies, including school attendance, social functioning, and academic performance. This preliminary investigation identified the persons with albinism’s pain status in Malaysia. Twenty persons with oculocutaneous albinism (OCA) with 20/200 visual acuity, aged between 17 to 65 years were assisted to answer a Standardised Nordic questionnaire for the analysis of musculoskeletal symptoms. Structured interview sessions based on Health Related Quality of Life Short Form (HRQL SF8), were also conducted at the office of Kuala Lumpur and Selangor Albinism Association and the Exercise Physiology Laboratory of UPSI. All (100%) the respondents experienced pain for the past 12 months, 95% claimed severe shoulder and neck pains, and 90% for the upper and lower back caused by wrong or awkward posture. Among those surveyed, 95% claimed to experience head and thorax pains, and 100% in the abdomen area. Photophobia was prevalent and hindered their daily activities. Despite experiencing severe pains, their quality of life was little affected. Due to the high pain prevalence, there is an urgent need for health promotion programmes to increase awareness on how to reduce pain. Pain management should include correcting their posture or by gadgets utilization. Subsequently, the current research team includes working on automated-raised reading table to ease PWAs to perform activities that require visual sense.

Keywords: albinism, HRQL SF8, musculoskeletal, pain, persons with albinism (PWA), Standard Nordic questionnaire