



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

Mai Shihah Abdullah¹

¹Department of Agricultural Science, Faculty of Technical and Vocational Education, Sultan Idris Education University, 35900 Tanjung Malim, Perak, Malaysia

Correspondence: Mai Shihah Abdullah (email: mai.shihah@fptv.upsi.edu.my)

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

Introduction

Back pain in Malaysia

The back pain problem that is very common among Malaysian ranges between 11.6%-84% compared to the world prevalence of 80% (Veerapen et al., 2007). They reported 11.6% out of 2600 respondents complained of back pain. Several occupational studies showed that workers were also prevalent with back pain. 74.4% among the male rubber workers in Federal Land and Development Authority (FELDA) settlement (Chow et al., 2012), 32% of oil palm plantation loader operators (Rosnah et al., 2007), 40.4% among primary school teachers in Klang Valley (Nurul Izzah et al., 2010), 84% among workers at food manufacturer (Baba et al., 2010), 60.4% among commercial vehicle drivers (Shamsul Bahri et al., 2007), 35.28% among nurses (Nur Azma et al., 2014) and 65.1% among doctors (Lee et al., 2014).

Although back pain severity was based on the respondents' belief, emotional response, and pain behaviour in response to pain (Main et al., 2011) extensive review was revealed that persistence of pain

was overwhelmingly prevalent in children and adolescents and should be recognized as a major health problem in a population (King et al., 2011). Not only lower back pain causes decrease in labour productivity due to off-work, absenteeism and early retirement (Tsuboi et al., 2002) it also signifies the poor quality of individuals' life due to physical, social and mental distractions (Tavafian et al., 2007) and definition by Main et al. (2011) showed that it also includes a range of perspectives, ranging from reference to highly psychological or social factors to a much broader umbrella that includes almost everything apart from biomedical factors.

Daily leisure reading activity among school children and adults in the USA was estimated between 4.2 minutes between 15-19 years old age group to 61.8 minutes among 75 years old adults. Nevertheless, the amount of time was reversed during the school days as children spend approximately 6 hours daily in school. Other than reading and performing classroom activities, much time was spent on walking between classrooms and carrying heavy school bags of 15% of their own body weight (Limon et al., 2004; Siambanes et al., 2004). Therefore, frequent school absence had been reported because of back pains. Roth-Isigkeit et al. (2005) reported that 19% of missing school were due to back pains. Absenteeism may limit opportunities for children to establish friendships, and may result in increased passivity. At the other extreme it may aggravate academic achievement. Hence, pain management should be provided till end-of-life (Leleszi & Lewansdowski, 2005) but interventions should commence as early as possible.

Albinism and their impairments

The world ratio of persons with albinism (PWA) to normal individuals is estimated at 1:17,000 (NOAH, 2015) and that makes 1,705 of Malaysian citizens carrying this genetic inheritance. The most severe form of albinism is called oculocutaneous albinism (OCA). They are affected by several genetic defects that make the body unable to produce or distribute melanin, a natural substance that gives colour to hair, skin, and iris of the eye. Research done in Malaysia have proven that they have been regarded as individuals with low-esteem, low academic competence, and low socioeconomic status, and visually-impaired (Sjodell et al., 1996; Summers, 1996; West et al., 2002; Mai Shihah, 2009). They have also been verified as less skillful compared to Australian PWAs in both finger movements and arm stability tests by two grades (Mai Shihah et al., 2012). Due to visual impairment and low motor skill (Mai Shihah, 2015), they have to lower their back in order to read and perform other tasks better but worsen their pain. Despite of all these problems, they lead a normal life (Omar & Fatin, 2008).

If normal school children encounter pain triggered by daily activities, what more among the children with albinism? To this date, no study has been conducted to investigate the status and pain management of pain among children with albinism and the factors associated with it. A self pain management approach could include training and education for school managers, parents and community in general. The concept of complete relief of pain is not always necessary for improvements in disability, mood and lifestyle would seem especially important for all to grasp (Blyth et al., 2005). There are also implications for resource allocation. The self pain management treatment can reduce the need for ongoing attendance at hospitals and multiple drug use. However, it requires skilled staff and time, especially in persons with albinism when facts about them are literally scarce.

Objectives of the study

This study is an attempt to investigate the pain among the PWAs with the objectives to

- a. estimate the pain prevalence among the persons with albinism, to
- b. determine the quality of life status due to pains among the persons with albinism, and to
- c. estimate the risk for factors associated with pains in PWA.

Methodology

Twenty persons with oculocutaneous albinism with 20/200 visual acuity aged between 17 to 65 years were assisted to answer an adapted Standardized Nordic questionnaire for the analysis of musculoskeletal complaints (MSC). Health Related Quality of Life Short Form (HRQL SF8) Questionnaire was modified to determine the pain status among PWA. The anatomic areas of pain were as indicated in Figure 1.

Factors associated with either anatomical pains and impairments such as severity of photophobia, reading font and reading aids were also included. Other informations on demographic data such as gender, age, marital status, occupation, education, visual acuity were also collected. A structured interview was conducted at the office of Kuala Lumpur and Selangor Albinism Association, Taman Tun Dr Ismail, Kuala Lumpur and the Exercise Physiology Laboratory, Faculty of Sports and Coaching, Sultan Idris Education University, Perak.

The collected data were analyzed using Statistical Package for Social Sciences (SPSS) version 19.0, and cross-tabulation, Chi-square and risk factor tests were done to identify the association between the anatomic pain areas and the factors involved. Descriptive data were also presented to provide an overall picture of the pain scale, and impairments among PWA.

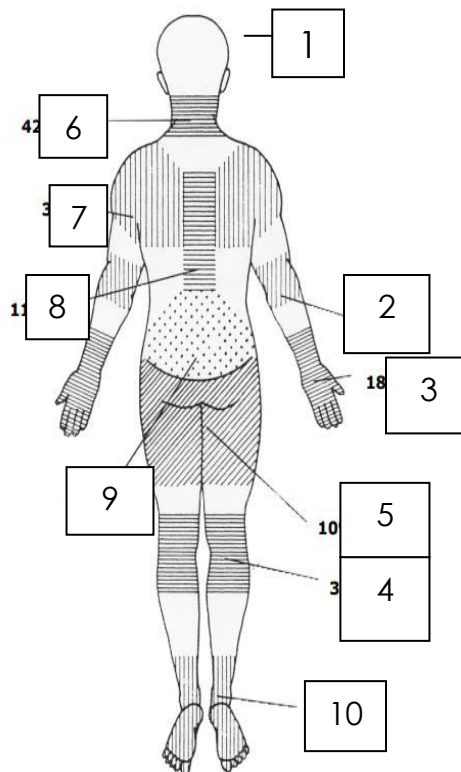


Figure 1. *Anatomic areas of pain*

Results and discussion

Sample characterizations

Gender and marital status.

Out of the 20 respondents, 9 (45%) were males and 11 (55%) were females. While 12 (60%) of the respondents were married (including divorces) and 8 (40%) were still single.

Age distribution.

The average age of the analysed samples was 34.15 (SD: 12.43) years with 25% of them were less than 20 years old, 50% were in the range of 21-40 years and the remaining 25% were 50 years and above.

Highest academic qualification and job types.

There were three (15%) post graduates degree holders, followed by one (5%) with Bachelor degree, 7 (35%) Diploma, 1 (5%) Certificate Level and the remaining 8 (40%) completed their upper secondary school. The jobs were categorized into three groups based on the involvement of physical activity; 25% fall under the strenuous labour and housekeeping, 35% active (marketing, production) and 40% sedentary (administration).

Reading font size

The visual acuity for all respondents was 20/200 and categorized as legally blind. When asked to identify their smallest readable font size administered during working or leisure as demonstrated in Table 1. "Headline" with the 72 font size used by elderly respondents aged 65 and 57 years old. They were able to read using the smallest font size 11 ("telephone book") by slanting their eyes. Font size 24 to 14 ("Large print books and Books / Textbooks") were the best options chosen by the respondents. None of them were able to read materials written using font size 9 (small advertisements).

Photophobia and reading aids

The problem faced by the respondents due to photophobia on a scale of 0 – 10 (none to worst) is presented in Table 2.

A high of 95% of the respondents reported that photophobia hindered their daily chores from a scale of 5 (medium) to 10 (worst) with mean= 6.85 and SD=1.84.

Reading aids are essential to assist reading among PWAs. All but one of them wore glasses, i.e. the most handy reading aid utilized by them. None of them was in possession of held-closed circuit television, but one possessed a desktop-closed circuit television. The contact lenses are still new as only 10% utilized them. Magnifying software was utilized by 30% of them. Monocular, binoculars and hand magnifying glass were among the best options (55%) after glasses used by the PWAs to assist their reading activities.

The speed of reading was documented as a major problem among them (Mai Shihah, 2009) but intervention using visual aids proven to solve this issue. Another study on the same respondent was done Omar and Fatin, 2008) as recommended by West et al. (2002) revealed that the majority of them did not have a problem with reading and handling related activities. They reported only 33% of the respondents were assisted by visual aid, but in this study, 95% of them were seen in possession and utilized at least one of the visual aids. Although PWAs were perceived as handicapped, they self claimed of the ability to perform daily tasks without much difficulty. Besides their daily chores, it is interested to note in this study that the high intensity of light from the sunlight and reading lights interfered with their reading speed (Sjodell et al., 1996; Mai Shihah, 2009).

Table 1. Smallest readable font size and administered during working or leisure

Font size	Working or Leisure	Smallest font size
Headlines	2 (10%)	
Large print books	6 (30%)	2 (10%)
Children's books	3 (15%)	2 (10%)
Books / Textbooks	6 (30%)	1 (5%)
Newspaper print	1 (5%)	2 (10%)
Telephone book	2 (10%)	13 (65%)
Small advertisements	0 (0%)	0 (0%)

Table 2. Effect of photophobia on persons with albinism

Scale	0	1	2	3	4	5	6	7	8	9	10
%	0	0	5	0	0	15	15	35	15	5	10

Prevalence of Musculoskeletal Complaints (MSC) in different body areas

In general, MSC was widely reported by the PWAs. Hence, 100% of the sample claimed that they had experienced MS either on the head, thorax or abdomen for the past 12 months. Figure 2 summarizes the prevalence of MSC in different body areas. PWAs reported that the most severe pains were on both the shoulder and neck (95%), followed by the lower and upper back (90%), due to wrong or awkward posture.

Pain for the past 12 months

Respondents were asked about their "pain" on the head (areas 1 and 6), thorax (areas 2 and 7) and abdomen (areas 8 and 9). The pain found to be the most prevalent was in the thorax area (mean scale = 5.65) followed by head area (mean scale = 4.65) and the least in the abdomen area (mean scale 4.20) (Table 3). The average pain scale among PWAs was 5.75 (min 2, max 8, SD 1.74) while their worst pain scale was 6.3 (min 2, max 8, SD 1.63). On average, they experienced the pains (on head, thorax and abdomen) between 4 to 10 times in the past 12 months, with 10% (2) of the respondents reported persistent pain.

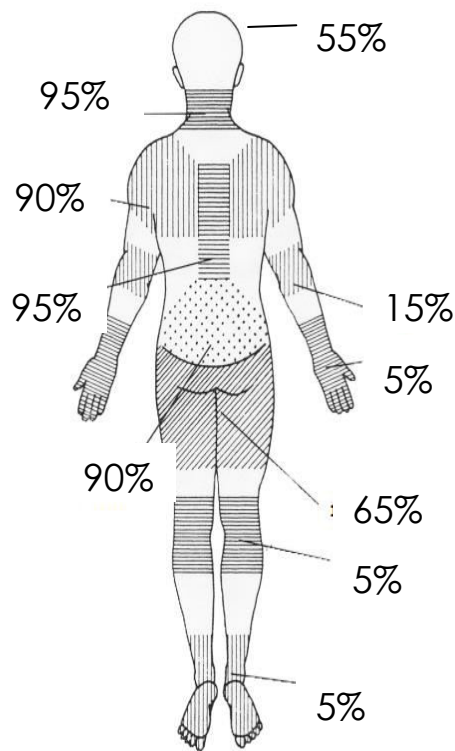


Figure 2. Prevalence of pain among PWA

Table 3. Pain scale among persons with albinism

Scale	0	1	2	3	4	5	6	7	8	9	10
	Head (mean= 4.65, SD= 1.99)										
%	5	5	15	5	5	25	35	0	5	0	0
	Thorax (mean = 5.65, SD= 1.98)										
%	0	5	25	5	5	30	10	15	5	0	0
	Abdomen (mean 4.20, SD 2.33)										
%	5	0	25	15	5	15	5	20	10	0	0

Risk factor of Musculoskeletal Complaints (MSC) in different body anatomical areas

Among those surveyed, 95% claimed to experience head and thorax pains, while 100% reported pain in the abdomen area. There was no significant difference between genders and pain in all the three areas ($\chi^2 = 1.287, p=.257$). A risk estimation study showed that the male PWAs had a low risk of 25% to 71% for all the three anatomical pain areas (OR .42, 95%CI: .249-.713). The shoulder area was identified to have the highest risk among PWAs ($\chi^2 = 16.296, p=.000$); OR 12.00, 95% CI: 1.837-78.369). The pain prevalence among PWAs (100%) is relatively high compared to previous studies done in Malaysia, i.e. it ranged between 11.6 - 84% when compared with and to the world prevalence of 80% (Veerapen et al, 2007). The pain prevalence studies in Malaysia reported by many authors are ranked and presented in Table 4. The pain experienced by PWAs is three folds greater compared to oil palm plantation loader operators.

Table 4. Pain prevalences reported in Malaysia

Rank	Prevalence	Year	Authors	Samples
1	100%	2014	Mai Shihah	Persons with Albinism
2	84%	2010	Baba et al.	Among workers at food manufacturer
3	74.4%	2012	Chow et al.	Among the male rubber workers in Federal Land and Development Authority (FELDA) settlement
4	65.1%	2014	Lee et al.	Among doctors in Selangor
5	60.4%	2007	Shamsul Bahri et al.	Among commercial vehicle drivers
6	40.4%	2010	Nurul Izzah et al.	Among primary school teachers in Klang Valley
7	35.28%	2014	Nur Azma et al.	Among nurses
8	32%	2007	Rosnah et al.	Oil palm plantation loader operators

The severe pains in both the shoulder and neck could be due to activities that require reading. Visual aids such as monocular, binoculars and hand magnifying glass used by the PWAs for a prolonged usage may carry some weight that adds to the pain. Furthermore, more PWAs are into the utilization of reading softwares that leads to usage of computers. It is known that working with computers makes one more prone to other musculoskeletal problems such as neck and shoulders. A PWA individual has to crane his/her neck while typing, thus making the shoulders and back muscles more tense hence resulting in more pain. Therefore, PWAs should be exposed to the correct ergonomic seating posture.

Conclusion and further research

This study concludes that the pain among the persons with albinism was highly prevalent. Although reading problem had been resolved by utilizing visual aid, the recurring shoulder and neck pains indicated that activity which required visual sensory remained as the main pain issue among them. Photophobia was more of a persistent problem that hindered PWAs daily activities.

Due to the high prevalence, pain management is recommended so as to take care of their back pains. There is an urgent need for health promotion programmes to increase awareness and to reduce pain among PWAs. There is a need for further research in order to achieve a better understanding of the risk factors present in a home, working and school environments and to address ways to reduce the currently recognized perceived problem of pain among PWAs. The risk factors associated with pain, the characteristics of the PWA individuals and the associated environments should also be investigated.

Further research should be directed towards investigating pain in the neck and shoulder regions and understanding the characteristics of symptom co-occurrence. Results in this study implicate the importance of inventing gadgets to assist them. At present it is undertaken by our research team epithet as Reading Automated Visual for Albinism (RAV4A), an automated-raised reading gadget to aid them to perform activities that require visual sense.

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