

# 'Culture in the clinic': A Review of the Public Health Challenge of Preventing Age-Related Low Vision or Blindness in African Americans: With Implications for Eye Health Care in Australia

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## ABSTRACT

There is a body of evidence indicating African Americans are at a higher risk of developing blindness or low vision from ageing-related eye conditions, largely due to lack of attendance at eye screenings or non-compliance with treatment. Three eye conditions which will be discussed in this context are cataract, glaucoma and diabetic retinopathy. The aim of this literature review is to demonstrate that, when planning programs such as eye screenings, it is important to consider the cultural needs of the client group under study. This paper attempts to demonstrate how addressing cultural needs and culturally-determined barriers to eye screening attendance could greatly enhance program success. Australia's cultural mix indicates there is a need to consider all races when planning programs. Using this holistic approach in a similar manner but applied to more local populations, such as indigenous Australians could also enhance eye screening attendance rates for these

subjects.

The literature suggests the health issue of low vision or blindness in African Americans is largely attributable to geographic and culturally-determined behavioural factors posing a barrier to seeking professional eye screening and treatment. Also, culturally determined barriers to modifying diet and lifestyle habits influence control of sight-threatening diabetes resulting in poorer vision, which generally deteriorates with age.

It has been reported that African Americans would benefit from public health intervention to help prevent or minimise low vision. If this health issue is successfully addressed, there could be significant reductions in the economic health care burden in regions where this population resides, and patients could enjoy a better quality of life.

**Keywords:** eye health, cultural attitudes, risk factors, barriers, enablers

## INTRODUCTION

According to public health professionals, health care delivery systems need to address the cultural needs of the targeted population in order to increase the likelihood of success.<sup>1,2</sup> This literature review aims to highlight the impact a well-planned, culturally appropriate eye health program can have on attendance rates and therapy adherence. Whilst this is an African American study, the results suggest that using the general approach of engaging with the target group in a culturally-sensitive manner could enhance program success in other populations. The holistic approach to health care can therefore be applied anywhere, if each culture is taken into account. Australia is a very appropriate example of a multicultural society which could take a similar approach to health care delivery.

Approximately 1 in 28 Americans over the age of 40 years are suffering with partial vision loss or complete blindness.<sup>3</sup> This rate is expected to double by the year 2020, as the population ages.<sup>4</sup> In African Americans, the problem is more prevalent and the challenge for orthoptists, ophthalmologists, optometrists and public health professionals working with these groups lies in addressing this gap.<sup>3</sup>

Low vision or blindness is costly to society as it affects independence, increases the risk of falls and comes with an expensive health burden to the community with the necessary incorporation of rehabilitative services. Vision loss also decreases living standards and quality of life. With vision-impaired individuals more likely to stay at home, the picture is further complicated as their connection with health professionals can potentially become more difficult to maintain.<sup>4</sup>

Various types of 'non-compliance' to medical intervention have been noted, a better understanding of which can

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assist in managing patients (Table 1).<sup>5</sup> Cataract, glaucoma and diabetic retinopathy are the three most common eye disorders. Visual outcomes related to these conditions can be improved if patients are educated about self-management and compliance with treatment. Eye health screenings planned in a culturally sensitive manner have been shown to improve compliance with suggested treatments when a diagnosis has been made.<sup>6,7</sup>

Table 1. Types of non-compliance with medical services in a US study of African Americans<sup>16</sup>

Receiving a prescription but not filling it
Taking an incorrect dose
Taking medication at the wrong times
Increasing or decreasing the frequency of doses
Stopping the treatment too soon
Delaying seeking healthcare or non-participation in clinic visits
Failure to follow doctor's instructions
'Drug holidays', the patient stops the therapy for a while and then restarts the therapy
'White-coat compliance', patients are compliant to the medication regimen around the time of clinic appointments

**PREVALENCE OF OCULAR CONDITIONS AMONGST AFRICAN AMERICANS**

**Cataract**

Cataracts are the cause of approximately 50% of cases of vision loss in white, African American, and Hispanic individuals, however the more severe forms of cataract-related vision loss are four times more prevalent in African Americans.<sup>8</sup> African Americans therefore have a greater burden of uncorrected cataract-related vision loss when compared with white Americans.<sup>8</sup>

**Glaucoma**

A recent study identified that glaucoma was present in 1.9% of people in the United States and three times more prevalent in African Americans.<sup>9,10</sup> There is therefore, an increased risk of vision loss in this population. Peek et al<sup>11</sup> also reported that African Americans are 45% less likely to undergo glaucoma surgery, which may be contributing to the higher blindness rates in this population.

**Diabetic retinopathy**

Diabetic retinopathy is present in 4.1 million American adults aged 40 years and over, with one in twelve having sight-threatening retinopathy. With future projections, the age-related prevalence of diabetes poses a serious public health challenge as the population ages.<sup>12</sup> Indeed, a 3.4 % increase in diabetes has been reported with age in a study of people over the age of 40 years.<sup>7</sup> Looking specifically at African Americans, it was noted that not only is diabetes more prevalent in this group, so is the most sight-threatening form of retinopathy where central vision is affected. This is

linked to having untreated diabetic retinopathy for a longer period of time.<sup>13</sup>

**RISK FACTORS**

**Biological factors**

The biological risk factors for glaucoma include a positive family history, or genetic predisposition, African American ancestry, and diabetes. Diabetes increases the risk of glaucoma, particularly when the diabetes is poorly managed and longstanding.<sup>9,10,11</sup> Diabetes is reported by Walker et al<sup>14</sup> to be more prevalent in African Americans, partly due to genetics, but also largely influenced by cultural factors.

**Cultural factors**

Cultural risk factors help to explain the attitudes, beliefs and consequent reactions to medical intervention. In a series of interviews with African Americans regarding cultural beliefs about the seriousness of vision loss; preferred health habits and a sense of spiritualism or 'fatalism' (that fate is in God's hands), were found to be possible influences on why medical compliance is poor.<sup>14</sup>

Furthermore, significant misunderstandings associated with the natural diet still consumed by many African Americans were noted. For instance, there was a lack of knowledge about a balanced diet. Many African Americans were reported to rely heavily on foods with high amounts of sugar, such as yams and bananas for nutrition, ignoring the other important food groups required in a diet.

**Environmental factors**

Environmental risk factors include geographical isolation, a low supply of eye health professionals or screening services in rural regions, or difficulty with transport to clinics for financial reasons. All these factors have been noted to be related to the increased prevalence of eye disease amongst African Americans.<sup>8</sup>

**BARRIERS TO HEALTHY BEHAVIOUR**

**Behavioural attributes**

The Eye Disease Prevalence Research Group<sup>12,15</sup> reported that African American men are more likely to be blind from cataracts than white men. In the East Baltimore region, untreated cataract and the resulting blindness was four times more prevalent in African Americans compared with whites. In addition, the types of cataracts found most frequently in African Americans are different from those found in whites.<sup>4, 15</sup> The cataracts are often diagnosed later in this population, due to poor attendance rates at eye screenings and are therefore of the more dense and central type, causing more severe vision impairment.

African American men are also more likely to have cataracts

resulting in total blindness even though more women are diagnosed with cataracts.<sup>8</sup> This is likely to be due to African American men being more likely to delay or completely avoid seeking surgical correction of the cataract.<sup>4</sup> Variations in access to surgical treatment may also account for some of these disparities.<sup>8</sup>

Looking at glaucoma, there was a higher reported incidence of vision impairment in African American versus white adults. Half of the blindness found in these populations could have been prevented or reversed with proper care, highlighting the need for attendance at screenings for early detection and compliance with treatment upon diagnosis. Studies of rural-based community populations showed that, as distance from the cities increased, the rates of vision loss from glaucoma were higher. This was reported to be partly due to lack of access to appropriate eye care.<sup>4</sup>

#### **Attitudes towards health, the health system and empowerment**

As noted previously, African Americans do not attend medical appointments as frequently as white Americans. A more in-depth analysis of reluctance to attend appointments was conducted by Brown<sup>16</sup> who undertook a series of individual interviews with African Americans. He reported that there was a level of mistrust in the advice and treatment offered by health professionals and that there was a preference for natural treatments to address poor vision.

Although this was a United Kingdom-based study, similar studies by Anderson et al<sup>17</sup> showed responders have feelings of powerlessness, ambivalence and even a fear of their illness. Both Brown and Anderson et al have shown an inability for African Americans to connect behaviour to outcomes and a lack of social support and education related to their health.<sup>16,17</sup> Other researchers however, have noted a lack of confidence in the health system, although this group still requested assistance from the same professionals they lacked faith in, to better understand their condition.<sup>18,19</sup> Overall, African Americans did not have a thorough understanding of the seriousness of the disease, lacked trust in the health system and did not possess the types of behaviours required to control an ocular and/or medical condition.

#### **Religious views**

Brown<sup>16</sup> reported that religious faith and the concept of leaving one's fate in the hands of a higher being (views embedded within the African American culture) are barriers to healthy behaviours. For instance, Peek et al<sup>11</sup> reported that African Americans are 45% less likely to undergo glaucoma surgery and suggested that this lack of co-operation with medical intervention may be due to religious views amongst other issues. Once again, issues of mistrust in the medical system, lack of understanding, fear and reluctance to change were also reported as reasons why African Americans underwent less surgery.<sup>11</sup>

#### **Language and lack of understanding of medical information**

Language can be a barrier when planning programs, as it hinders communication and understanding of the information provided regarding diagnosis and treatment.<sup>20</sup> African Americans speak in a range of unique ways. Included in the language is a variation on English, described as 'African American English', 'bad', 'simple' or 'Pidgin English'.<sup>21</sup> Whilst the language may not immediately appear to be much of a variation on English, the use of this type of language creates a sense of identity amongst group members.<sup>21</sup> It is this latter point which health professionals could take note of when planning programs. An interpreter may not be required, but placing participants together in groups with members they can relate to, has significantly enhanced program success rates.<sup>11</sup>

When researchers looked at perceived barriers to diabetic eye care, they found that whilst participants felt they had a good knowledge of the condition, there was a gap in the levels of information relayed about retinopathy and in subsequent patient understanding.<sup>14,22</sup> All suggested that addressing language barriers may help to bridge this knowledge gap.<sup>14,18,19,22</sup> Walker<sup>14</sup> also reported that in the case of diabetes, complications of the general disease can overshadow the eye disease, further complicating understanding and compliance.

#### **ENABLERS TO IMPROVING ATTENDANCE AT VISION SCREENING AND CHECK-UP SERVICES**

In the interviews conducted by Brown,<sup>16</sup> group discussion proved to be an effective method in increasing participants' understanding of their condition. African Americans felt most comfortable in a setting with their peers and this has proven an enabler to public health education.<sup>11,23</sup> Also encouraged is a more personal approach, with individual phone-calls to patients to follow up on any educational programs implemented.

Useful strategies to enable effective delivery of health messages to target audiences include the use of the mass media, interpersonal communication and shared decision-making. In general, it has been found that individuals are willing to learn more about their eyes and the potential for sight loss, which is driven by a sense of fear and stress about losing vision<sup>11</sup> and as such, there is significant opportunity for clinicians to enable increased understanding.

Given that it is well known that early detection is a key to preventing vision loss, it is questioned whether adequate numbers of eye care professionals exist in rural areas where African Americans reside. Increasing the access to eye screenings in rural areas is therefore also a necessary step in public health intervention, in addition to better educating African Americans about their eye condition and working on modifying behaviours and attitudes.

**PUTTING THE EVIDENCE INTO THE AUSTRALIAN CONTEXT**

The Australian Bureau of Statistics (ABS) reports national census data however lengthy demographic census reports are not published on a yearly basis, but rather five-yearly.

A general trend of immigration of all races is increasing. The National Migrant Statistics Unit (NMSU) was developed in 2006 by the ABS.<sup>24</sup> Not all ancestry is reported accurately, however in 2011 the reported immigration of those with African American ancestry was at least 1,141. Migration is increasing, and as not all ancestries are reported, or some people report only one of two ancestries, this figure is likely to be significantly higher.<sup>25</sup>

In 2013, the ABS census data showed that in the last ten years, immigration to Australia in general, has grown from 23.1% to 27%, or to approximately 6 million people. This is a significant change, so it stands to reason that health care professionals must take the culture of the patient into account, to enhance effectiveness in service delivery.<sup>25</sup>

**CONCLUSION**

The evidence presented here, points to a significant gap in eye health between white and African Americans. The literature suggests that this is explained by behavioural and environmental risk factors, cementing an already existing lack of compliance with and understanding of medical services.

The picture is not completely negative, as efforts to improve knowledge gaps to date have shown possible enablers to change, such as a concern about health and a willingness to learn more. The challenge for the future now lies in matching public health programs to the needs of target groups. Australian health professionals should be alert to the fact that they may come across members of this demographic in their daily working lives. Principles outlined in this review could be applied to enhance program success. Similarly, clinicians are encouraged to take a more holistic approach when planning any eye health program, by ensuring it matches the overall needs of the particular target group from the outset.

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