



# The experience of people with oculocutaneous albinism

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This article reports the experiences of people with oculocutaneous albinism in South Africa. Oculocutaneous albinism is an inherited disorder characterised by the defective production of melanin, with little or no pigmentation in the skin, hair and eyes. This condition is found globally, with a high prevalence in sub-Saharan Africa and in clusters in South America. People with this condition are often stigmatised and discriminated against owing to myths and superstitions held by the public about the condition. To date no studies have explored the psychosocial aspects of oculocutaneous albinism. A qualitative study was conducted in Johannesburg, South Africa during 2007 where a purposive sample of 15 members of the black population with oculocutaneous albinism participated in in-depth individual phenomenological interviews. One central question was posed to facilitate the interviews: Could you please share your experience as a person with albinism? Data from the interviews were analysed using Collaizi's qualitative data analysis method and three main themes emerged: (1) perceptions of the internal environment, for example the self; (2) experiences in the external environment, for example family and community; and (3) the need for self-development and growth based on their experiences. Recommendations are made to enhance the self-concept of and promote a sense of belonging, self-development and growth in people with oculocutaneous albinism.

Hierdie aanbieding is 'n verslag oor bevindings van die ervaring van persone met okulokutaneuse albinisme in Suid-Afrika. Okulokutaneuse albinisme is 'n oorerflike afwyking, gekenmerk deur 'n gebrekkige melanien produksie. Daar is min of geen pigmentasie in die vel, hare en oë nie. Hierdie toestand word wêreldwyd aangetref met 'n hoër voorkoms in sub-Sahara Afrika en groepe in Suid Amerika. Mense met hierdie toestand het dikwels 'n stigma en daar word teen hulle gediskrimineer as gevolg van mites en bygelowe van die publiek oor die toestand. Tot datum het geen studies die psigososiale aspek van hierdie toestand ondersoek nie. 'n Kwalitatiewe studie is in Johannesburg, Suid-Afrika uitgevoer in 2007. 'n Doelgerigte steekproef van 15 swart mense met okulokutaneuse albinisme het deel geneem aan in diepte individuele fenomenologiese onderhoude. 'n Sentrale vraag was gestel om die onderhoude te fasiliteer: Kan u asseblief u ervaring as 'n persoon met albinisme deel?'" Data van die onderhoude was geanaliseer deur van Collaizi's se kwalitatiewe data analise metode gebruik te maak. Drie hooftemas het te voorskyn gekom, naamlik: (1) persepsies van die interne omgewing byvoorbeeld die self; (2) ervarings van die eksterne omgewing, byvoorbeeld die familie en die gemeenskap; en (3) die behoefte vir self ontwikkeling en groei gebaseer op hulle ervarings. Aanbevelings is gemaak deur die navorsers om self konsep uit te lig, en om 'n gevoel van 'behoort aan', self ontwikkeling en groei in mense met okulokutaneuse albinisme te bevorder.

## Introduction

Oculocutaneous albinism is an inherited disorder characterised by absent or minimal production of a pigment called melanin. As a result, pigmentation is absent from or diminished in the skin, hair and eyes. The condition is inherited in an autosomal recessive manner, which implies that the person with oculocutaneous albinism inherits two faulty genes, one from each parent. Both parents of the person with oculocutaneous albinism may appear unaffected but carry one faulty and one normal gene each (Christianson, Howson & Modell 2006; Winship 2003).

Owing to the absent or minimal production of melanin, people with oculocutaneous albinism are affected by a variety of physical and physiological conditions, including marked sensitivity of the skin and increased risk of skin cancer caused by over-exposure to the sun. Whilst in most individuals with this condition the skin completely lacks pigment, in some it may appear blotchy. In addition, persons with oculocutaneous albinism may present with abnormal development of the optic nerve, which may result in poor vision and nystagmus (Christianson *et al.* 2006; Winship



2003). Although the person with oculocutaneous albinism has to cope with these biological threats, the literature reveals that the major challenge faced by people with oculocutaneous albinism in most societies is stigma and prejudice caused by myths, superstitions and misinformation (Christianson *et al.* 2006; Winship 2003).

The primary researcher and co-researcher have more than 16 years' experience of interacting with people with oculocutaneous albinism. The co-researcher is a geneticist who has conducted various studies on oculocutaneous albinism and other congenital defects. The researcher has observed with concern that despite the efforts of various stakeholders to raise awareness of oculocutaneous albinism and other congenital disorders, and despite various studies conducted, stigma and the marginalisation of people with oculocutaneous albinism continues in many communities.

In this regard, the Save the Children Research Report (2001) emphasises that stigma and discrimination have an insidious impact on the self-image and self-respect of the individual being stigmatised. This finding triggered the need to conduct a qualitative phenomenological study, and this article presents research findings on the life experience of people with oculocutaneous albinism in Gauteng, South Africa.

A preliminary literature review was undertaken to verify the need to conduct such a study. Christianson *et al.* (2006) report that oculocutaneous albinism is found globally, but with a high prevalence in sub-Saharan Africa and in clusters in South America. Various studies show that congenital disorders, including oculocutaneous albinism, are global challenges that need practical and comprehensive intervention.

It is evident from the literature review that extensive epidemiological studies have been conducted on oculocutaneous albinism. It is also evident that some of these studies are not current, although their findings are significant for this study. For example, Kromberg, Castle, Zwane and Jenkins (1989) conducted studies on oculocutaneous albinism in South Africa between 1982 and 1999. Kromberg and Jenkins (1982) recorded a prevalence rate of oculocutaneous albinism of approximately 1 in 3 900 in Johannesburg, South Africa, compared with 1 in 9 635 in Norway and Sweden. The South African prevalence rate (1 in 3 900) is higher than in other parts of Africa, such as Nigeria, where it has been reported to be 1 in 5 000 (Kromberg & Jenkins 1982).

Between 1999 and 2003 other studies were conducted in South Africa on congenital disorders relevant to oculocutaneous albinism (Bhagwanjee & Sterwart 1999; Gaigher, Lund & Makuya 2002; Moodley 2003; Mweshi & Mpofu 2001). In addition, international studies relevant to oculocutaneous albinism were conducted by Liascovich, Castilla and Ritter (2001) in South America, and by Lund, Puri, Durham-Perrie, King and Brilliant (1997) in Zimbabwe.

Prior research on oculocutaneous albinism focused mainly on epidemiological factors and congenital characteristics, and to

a limited extent on the psychosocial impact of stigma and marginalisation. Most importantly, Kromberg (1992) reports that oculocutaneous albinism is more common amongst the South African black population than it is amongst whites in Europe. This background triggered the need to explore the life experiences of people with oculocutaneous albinism in the black population in South Africa. The relevant research question was as follows:

'What are the life experience of people with oculocutaneous albinism and what does it mean to them to have this congenital disorder?'

## Problem statement

Owing to the explorative nature of this research, the primary researcher entered the field with an open mind. In addition, the researcher bracketed all prior knowledge on the phenomenon under investigation. In terms of the Neuman's systems model, a person with oculocutaneous albinism presents with five interacting dimensions, physiological, psychological, socio-cultural, spiritual and developmental (Neuman 1995; Stanhope & Lancaster 2000). The researcher considered these comprehensive dimensions as basic categories essential in enhancing the self-concept of people with oculocutaneous albinism. The research findings were reflected within these major dimensions of Neuman's systems model after data analysis to give them structure, but were not forced to fit within the model.

## Research purpose

In accordance with the research question, the main purpose of this study was to explore and describe the life experiences of people with oculocutaneous albinism.

## Research significance

The authors observed with concern that despite the efforts of the Department of Health in South Africa to raise awareness and train health professionals, there was still a lack of knowledge of oculocutaneous albinism amongst both health professionals and the community. Lack of knowledge results in negative attitudes by the community towards people with this disorder. It is hoped that this article will help identify issues of concern that need to be addressed amongst people living with this condition.

## Research methods and design

### Design

A qualitative phenomenological research design was used to explore and describe the life experiences of people with oculocutaneous albinism. A qualitative approach was essential to collect rich narrative data, and the explorative nature of this research gave people with oculocutaneous albinism an opportunity to describe their life-world in a natural setting, in their own words and in as much detail as possible (Polit & Beck 2004).

A phenomenological research methodology helped the researcher gain a deeper understanding of the meaning of



the everyday experiences of people with oculocutaneous albinism (Fain 2004:220). This approach was used to structure the research and to select an appropriate sample, collect data and analyse information systematically.

## Population and sampling

The population consisted of black females and males with oculocutaneous albinism who met the sampling criteria of having oculocutaneous albinism, having first-hand experience of the condition, and being able to articulate their life experience. A purposive sample of 15 people with oculocutaneous albinism participated in the study, 12 females and three males aged between 18 and 48 years. The primary researcher accessed the research participants through the Albinism Society of South Africa (ASSA); those residing in Johannesburg were identified randomly from the data bases of the society (13 of the 15 participants were members of ASSA). After being selected initial contact was made by the primary researcher as a way of introducing the study. An initial telephone conversation was held followed by a face-to-face, in-depth individual interview.

Arrangements were made with the participants telephonically to negotiate a suitable time and venue for the interviews. A pilot study comprising two interviews was conducted during the second week of January 2006, a week before conducting the main study. The primary researcher gained valuable experience during the pilot interviews, which helped provide proper knowledge and skills to facilitate in-depth interviews and facilitated the data collection and analysis process of the main study (Polit & Beck 2004). The pilot interviews were included in the final data analysis of the study.

## Data collection method

The primary researcher conducted the face-to-face, in-depth individual phenomenological interviews over a three-month period between January and March 2006. Consent forms were signed by participants and the interviews were conducted in their homes.

Other family members were cooperative, and the interviews were conducted with minimal disturbance, each lasting between one and two hours.

In-depth individual phenomenological interviews were essential to obtain an 'emic' view or insider's perspective of oculocutaneous albinism (Polit & Beck 2004). Another advantage was that some of the participants expressed appreciation that the researcher wanted to listen, as they shared their experience on issues that seemed to be difficult to disclose to other people. In this regard, one of the participants remarked as follows:

'Hmm ... but I'm glad you came to ask me this ... for I bottled it up all the time ... and I didn't know who to speak to about the staff ... About why they criticise us...' (Participant)

An interview protocol was used during the interviews, and conversation with the study participants was facilitated by

the following grand tour question: 'Could you please share with me as thoroughly and honestly as you can your life experience as a person with albinism.' Other facilitative communication techniques, which include probing, clarifying and non-verbal encouragement, were used to inspire the participants to share their life-experience on living with oculocutaneous albinism.

A voice recorder was used with the permission of the study participants to capture the discussions during the interviews. The researcher also kept field notes to provide enough contextual information on the life-experience in a social setting (Polit & Beck 2004).

Interviews were conducted with the fifteen study participants until data saturation was achieved, that is, when the ideas surfacing in the dialogue had been previously heard from other participants (Fain 2004:226). Most importantly, direct quotations of the research participants were captured during data collection and analysis so as to reflect the true personal experiences of people with oculocutaneous albinism.

## Data analysis

The researchers used Collaizzi's six basic principles of qualitative analysis (Polit & Beck 2004:585; Streubert & Carpenter 1999) to systematically analyse the data as follows:

- Transcribing the tape-recorded interviews word for word, cross-checking against the field notes, and preparing data in an accessible visual written format using Microsoft Word.
- Extracting significant statements from the transcripts, and assigning sentences and paragraphs to the labelled categories.
- Focusing on the essence on oculocutaneous albinism, and points of significance to formulate ideas on the participants' life-experience.
- Identifying themes to facilitate discussion on the research findings, and integrating the themes into an exhaustive description of the participants' experience.
- Conducting follow-up interviews with six of the study participants to ensure that the findings reflect the thoughts and feelings of the participants, and not the researcher's ideas.
- Conducting a literature control to make sense of the research findings.

## Research findings and literature control

It became clear during the data collection and analysis process that myths, superstitions and stigma are major challenges faced by people with oculocutaneous albinism. However, what is positive in the findings of this study is that the participants felt very strongly that they 'themselves' should eradicate those myths and superstitions; they should maintain their self-worth; and they should show the world that they too deserve to be treated with dignity as others are.



Most importantly, the findings revealed that self-concept is a fundamental aspect of the participants' life-world. The findings also revealed that the external environment plays a fundamental role in enhancing the self-concept of people with oculocutaneous albinism. Three main themes were identified: (1) participants' perception of their self-concept; (2) participants' experience in the external environment; and (3) participants' expression of the need for growth and development. Concurrent with data collection and analysis, an extensive literature control was undertaken to identify similarities and differences in the findings of this study compared to previous research. A comprehensive discussion of the findings is dealt with in the themes below.

### Theme 1: The participants' perception of self-concept

Self-concept became the focus of the first theme. The majority of participants recognised that they 'themselves' play an important role in their own lives. Of the fifteen participants, fourteen felt very strongly that the onus is on the 'self-concept' of the persons with oculocutaneous albinism to improve their self-worth in the community. In this theme two categories emerged namely: (1) the importance of self concept and (2) the role of family in enhancing the self-concept of an individual with oculocutaneous albinism.

#### Importance of the self-concept

Literature confirms the importance of the 'self-concept' by indicating that the 'self' constitutes people's awareness of their individual existence. In addition, literature reveals that there is an 'inner self' through which an individual experiences the self and the world (DuBois 2003; Jordaan & Jordaan 1998).

Attributes of self-concept revealed in the present study include self-actualisation, self-esteem and self-worthiness. In the self-actualisation process, people strive to discover their true potential (Jordaan & Jordaan 1998). In this regard, the participants realised their self-actualisation as follows:

'I think we should go out to the people ...', "Others they are still locked in the houses ... there is no need to be afraid and hideaway ...", "ok, there is information on albinism ... but we must go out raise awareness on oculocutaneous albinism.' (Participant)

Self-esteem is associated with having a positive attitude or acceptance of oneself (DuBois 2003; Jordaan & Jordaan 1998). It emerged in the findings of this study that the self-esteem of the participants who were members of ASSA was high. The study participants appreciated the support provided by ASSA:

'... because what they do at Albinism Society is counselling ... and you get a lot of information ... and you also accept yourself ...' '... the main purpose of the Society is to help you accept yourself ...' (Participant)

The participants experienced self-worth in different ways, especially with regard to employment status. It was evident that there was a strong feeling that being employed enhanced

one's self-esteem. For instance, during interview session, one of the participants concluded as follows:

'My main concern is for me to get a job. I don't know. That's how I feel. Ja, maybe it will improve the way I feel now, maybe it will be different. Not working is making me feel less of myself ...' (Participant)

According to Maslow's self-actualisation theory (Maslow 1970), the need for self actualisation for is based on the fact that people need to feel 'self-respect', have a sense of their own value, and should feel respected and appreciated by other people. In line with Maslow's self-actualisation theory, it emerged in the findings of this research that the family and community play a fundamental role in enhancing the self-concept of people with oculocutaneous albinism.

#### Role of the family in enhancing self-concept

As the participants related their life experiences, they felt very strongly that the family plays a significant role in enhancing their self-concept. As one of the participants stated when talking about her anchor in life:

'It's my family ... It's my family ... nothing else. I mean it. They are the only people that before you can convince people outside they parents should convince them community.' (Participant)

Literature supports the important role of the family in enhancing a person's self-esteem. The family is regarded as the primary environment for rearing a child (Dell-Orto & Marinelli 1995:44). This study revealed that families of people with oculocutaneous albinism and families without people with oculocutaneous albinism both have a social role to play in enhancing the self-esteem and in the development and growth of people with oculocutaneous albinism.

An important aspect that emerged in this study was that the participants' parents were not overprotective of their children with oculocutaneous albinism. It is assumed that the parents not being overprotective enhanced the participants' self-esteem, confidence and self-acceptance. In this regard, Gaigher *et al.* (2002) emphasise that if rejection starts from birth, the chances are high that the person with oculocutaneous albinism will later succumb to the community's negative attitudes and stereotypes.

The 'self-concept' was found to be important as it relates to the other two themes of this research. The findings reveal that the participants recognised the significant role of the external environment, especially the community, in enhancing the 'self-concept' of people with oculocutaneous albinism. Consequently, the participants' experience in the external environment was identified as the second theme of the research findings.

### Theme 2: Participants' experience in the external environment

It emerged that the participants' interaction with the external environment influenced their self-image and a sense of belonging at home and in the community. In line with most





previous studies (Gaigher et al 2002; Kromberg 1992; Pooe-Monyemore 2003), stigma and prejudice in the community emerged as a major challenge faced by most people with oculocutaneous albinism.

### Stigma due to skin colour

The participants felt socially stigmatised on the basis of their skin colour, which was very obvious owing to having little or no pigmentation. According to Link and Phelan (2001), stigma is usually associated with a deviation from what is normally expected.

Nevertheless, Gaigher *et al.* (2002) argue that the problems experienced by persons with oculocutaneous albinism do not necessarily relate to their obvious physical difference in terms of skin colour, but to the social environment that they have to cope with, which is also influenced by myths and superstitions in the community.

### Stigma due to myths and superstitions

It emerged clearly in this study that myths and superstitions about oculocutaneous albinism affected the participants' everyday social life and self-image. The participants willingly shared their experiences of such myths and superstitions. All expressed their concern about the most common myth that people with oculocutaneous albinism "do not die naturally but simply disappear or vanish".

However, the participants differed in their reaction to this myth. Most felt that this myth should be a starting point for educating the community on oculocutaneous albinism. Others were insulted by it, but felt very strongly that people with oculocutaneous albinism should unite to eradicate this 'disappearing and/or death' myth:

'... those who don't understand that we are people, and so on, the issues of disappearing, we must be there, all people with albinism.'

'OK, there is information on albinism, but we must go out to eradicate the myth that we disappear.' (Participant)

Kromberg (1992) also found the 'disappearing and/or death' myth to be most common amongst the South African black population, and suggests that it may be based in the distant past when people with oculocutaneous albinism were believed to be the product of a woman and a water spirit. Kromberg (1992) is also of the opinion that a practical explanation for this myth could be that many people may not have seen people with oculocutaneous albinism pass on or die. The participants shared their experiences of how this myth and other superstitions have psychosocial implications for them. In support of this, Jordaan and Jordaan (1998) point out that beliefs in society affect people's attitudes to life, as well as behaviour in religious, ethical, political and social contexts in the environment.

The findings of this research also revealed that self-image and the external environment influenced the self-development and growth of people with oculocutaneous albinism. The

participants' expression of a need for development and growth was therefore identified as the third and last theme of the research findings.

### Theme 3: Participants' expression of need for development and growth

Besides the role of the family and community, it emerged that the external environment, consisting of various stakeholders including Government departments, non-governmental organisations, the media and the private sector, influence the self-image and development and growth processes of persons with oculocutaneous albinism. It was evident that the role of various Government departments in the lives of people with oculocutaneous albinism should not be underestimated.

#### Role of various Government departments

It emerged in this study that the most important Government departments in enhancing confidence and promoting the development and growth of people with oculocutaneous albinism are those of Health and Education. The study found that the Department of Health plays a major role, especially in terms of providing skin care treatments and counselling for people with oculocutaneous albinism and their families, and raising awareness of the condition.

Most of the participants expressed their appreciation that the Department of Health is making an effort to raise awareness of oculocutaneous albinism. Nonetheless, others felt that information on the condition is insufficient, and that the Department of Health should increase awareness raising and provide creams with a sun protective factor of 25 or above as recommended in Department of Health policy. In line with this finding, Gaigher *et al.* (2002) note the fundamental role of the Department of Health, and emphasise that specialised, accessible and people-friendly health care is necessary for the care of people with the condition.

With regard to the role of the Department of Education, the participants felt very strongly that educators at schools should be knowledgeable on oculocutaneous albinism. They suggested that with this knowledge the educator will be able to enhance self-esteem in learners with the condition, and thus promote development and growth. It also emerged that the school plays a fundamental role in nurturing a sense of belonging in learners with the condition.

The participants noted the role of other departments, including the Department of Labour. In this regard, the Department of Labour's role was noted as helping with employment for people with oculocutaneous albinism as well as learnership programmes. The findings of this study revealed that participants who were not employed felt that they had not been given a chance to develop and grow:

'... mostly they [people with oculocutaneous albinism] are unemployed ... and so if ... that's why I say people with albinism are not necessarily treated as normal people in all instances ... it's hard for them to be employed ...' (Participant)



The participants also noted the role of the Department of Social Development in granting disability grants to people with oculocutaneous albinism who qualify. The Department of Science and Technology was also cited as improving advanced technology for people with the condition, especially those with eyesight problems.

### Role of non-governmental organisations

It emerged from the research that the participants value the power and security of non-governmental organisations in their social development and growth, particularly ASSA.

The participants greatly appreciated the way in which ASSA enhanced their self-esteem by providing counselling, raising awareness of oculocutaneous albinism, encouraging them to recognise their rights, providing them with other support services, and referring them when the need arose. However, other participants felt that ASSA should be more visible in other areas:

‘ASSA helped me to socialise with other people with albinism ... but with other things ... and I think there is a need to have ASSA in other areas ... because I used to be isolated ... but now at ASSA I could relate and say OK we used to share experience.’ (Participant)

The role of ASSA confirms that a collection of people can only be considered a group if it displays certain attributes (Jordaan & Jordaan 1998). In this regard, according to the Chairperson of ASSA, establishment of ASSA in 1992 was initiated by the community’s rejection of people with oculocutaneous albinism (Ngakane 1998). Without a doubt, the participants felt very strongly that ASSA should be strengthened to enhance the self-concept of people with oculocutaneous albinism.

### Role of the private sector

It emerged in this study that the role of the private sector in promoting development and growth of people with oculocutaneous albinism should also not be underestimated. The participants felt that in as much as the Government should be concerned with the development and growth of people with oculocutaneous albinism, the private sector also should seriously note its important role:

‘I think you are doing enough as Government. My concern is with the private sector. I don’t know whether they don’t have access to information. For example, banks and private companies and so on and so on ... I don’t know whether it’s because they don’t want to know or they can’t access information.’ (Participant)

### Role of the media

All of the participants noted that the media should play a significant role in developmental programmes for albinism. However, most raised concerns that the media is not doing enough to raise awareness of oculocutaneous albinism:

‘Awareness on albinism is not raised enough in the media ... That’s why most people don’t understand what albinism is, and how to treat a child with albinism.’ (Participant)

It is evident from the findings of this research that the participants felt strongly that enhancing self-concept, promoting a sense of belonging and promoting development and growth, are essential concepts in the lives of people with oculocutaneous albinism. The next section therefore discusses and recommends relevant strategies to address these concepts.

## Ethical considerations

The Health Studies Research and Ethics Committee of the University of South Africa granted ethical approval for the study. The Research Committee of ASSA also granted approval for members of ASSA to participate in the study.

Full details of the study were given to potential participants, and their rights to anonymity, confidentiality and withdrawal without prejudice were explained. Informed written consent was obtained from each participant. Most importantly, to ensure that trustworthy data were collected, an appropriate explorative research design was used to facilitate an open and honest discussion on oculocutaneous albinism.

## Trustworthiness

The researcher enhanced trustworthiness of the study by using Guba’s four criteria, namely: 1) truth value, using strategies of credibility; 2) applicability, using strategies of transferability; 3) consistency, using strategies of dependability; and 4) neutrality, using strategies of confirmability.

## Discussion and recommendations

In line with the findings of this research, strategies to enhance the self-concept, promote a sense of belonging, and promote development and growth of people with oculocutaneous albinism are recommended.

### Strategies to enhance self-concept

The researcher used the findings of this research and the literature as the basis for developing strategies to enhance the self-concept of people with oculocutaneous albinism as follows:

- Professionals, especially in the Departments of Health and Education, should enhance self-image and self-knowledge by providing basic information on oculocutaneous albinism to the people affected and their families.
- This information should include the pattern of inheritance, skin and eye care, and the importance of using appropriate sun protective moisturisers. Information should also be provided on available resources and support groups.
- Professionals should encourage self-awareness of the person with oculocutaneous albinism, since this is essential for the person to realise his or her maximum potential (Friedland 2005).
- Prinsloo (1995) suggests that the person with oculocutaneous albinism should keep in mind that the concept of human ‘worth’ is relative, and its meaning depends on who defines it.



- Persons with this condition should note Prinsloo's (1995) emphasis on self-esteem and self-worth: "You have to realise that the only person's opinion that really counts is your own."
- It is therefore fundamental that the person with oculocutaneous albinism should enhance his or her self-worth, and promote their own sense of belonging with the necessary support from the family and community.

### Strategies to promote own sense of belonging

Self-esteem is the perception of being accepted and valued by the family and the community. Prinsloo (1995) and Goleman (1997) encourage the person with oculocutaneous albinism to promote his or her own sense of belonging by:

- Doing things that he or she finds interesting and stimulating in the community. The person should also confront daily problems and derive satisfaction from figuring out how to solve these.
- Fighting back against invalid negative thoughts about him or herself. The person should train him or herself to recognise self-critical thoughts as they go through the mind, and should practise dealing with these thoughts.
- Thinking positively, because positive thinking is a source of happiness which will promote personal development and growth.

### Strategies to promote self-development and growth

The following strategies are recommended to promote self-development and growth in persons with oculocutaneous albinism:

- The health professional should encourage people with oculocutaneous albinism to set goals, develop workable plans for their own growth, and make contracts with themselves to implement those plans (Clinebell 1992; Goleman 1997).
- The ultimate goal of promoting the person's development and growth is to liberate his or her potential in all dimensions of his or her life, beginning with inner liberation. Clinebell (1992) is of the opinion that in the process of growth there is a fundamental respect for the ways in which each individual wants to change and grow.
- The external environment should be non-threatening and non-judgemental so that the person with oculocutaneous albinism can develop a sense of belonging, stimulate inner liberation and enhance self-worthiness.

### Further research

Self-concept surfaced as a fundamental concept in this study. Further research on 'self-concept' is essential so as to determine the 'inner or real self' of people with oculocutaneous albinism. The effect of the environment in enhancing the self-concept of people with oculocutaneous albinism should be investigated further. In addition, the role of non-governmental organisations to promote self-development and growth of people with oculocutaneous albinism and/or congenital disorders should be determined.

### Nursing education

Nursing training modules and curriculum should equip nurses with the necessary skills and knowledge of congenital disorders, including oculocutaneous albinism.

Although nurses in South Africa and elsewhere in the world receive basic training on congenital disorders during their training, there is evidence that this basic training does not improve their knowledge of congenital disorders (Christianson et al 2006).

### Policy making

It is evident in the findings of this research that various Government departments play an important role in the lives of persons with oculocutaneous albinism, especially the Departments of Health and Education. It is essential that these departments should orientate health professionals on the availability and implementation of policies pertaining to oculocutaneous albinism and/or other congenital disorders.

People with oculocutaneous albinism and their families should be involved in the development and implementation of these policies. This, in turn, will enhance their self-esteem, and promote a sense of belonging as well as self-development and growth.

### Limitations of the study

The sample size and mode of inquiry, which is qualitative by nature, limits the generalisation of the study findings. In future, studies investigating congenital disorders could benefit from a broader sample. However, the population size of people with this disorder is small.

### Conclusion

The findings of this research and the above discussion clearly indicate that priority issues on oculocutaneous albinism, especially with regard to self-concept, should be pursued in future research. In addition, attention should be given to nursing education and policy making to integrate these concepts.

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### Competing interest

The authors declare that they have no financial or personal relationship(s) which may have inappropriately influenced them in writing this article.

### Author contribution

M.B.J. (University of South Africa) was the doctoral candidate that conducted the research. T.R.M. (University of South Africa)



supervised the conduct of the project and A.L.C. (University of South Africa) was a joint supervisor of the thesis.

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