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Exploring the occupational engagement experiences of individuals with oculocutaneous albinism: an eThekwini district study 1) Lara Mather B.OccTh (UKZN) Community Service Occupational Therapist at Ekombe Hospital Contact number: 0845020369 Email:Laramather1995@gmail.com Orchid ID:https://orcid.org/0000-0002-0365-7951 2) Ms T Gurayah B.OccTh (UDW), M.OccTh (UKZN) Lecturer Discipline of Occupational Therapy School of Health Sciences University of Kwa-Zulu Natal Contact number: 076 600 6184 Email: Gurayaht@ukzn.ac.za Orchid ID: https://orcid.org/0000-0001-9005-6355 3) Dr Deshini Naidoo B. OccTh (UDW), M. OccTh (UKZN), PhD (UKZN) Lecturer Discipline of Occupational Therapy School of Health Sciences University of Kwa-Zulu Natal Contact number: 031 260 8407 Email: Naidoodes@ukzn.ac.za Orchid ID: https

://orcid.org/0000-0001-6276-221X 4) Henna Nathoo B.OccTh (UZKN) Community Service Occupational Therapist at Dr Yusuf Dadoo Hospital Contact number: 082 836 1885 Email: hnathoo97@gmail.com Orchid ID: https://orcid.org/0000-0002-0916-6299 5) Fortune Feresu B.OccTh (UZKN) Contact number: 077 256 8042 Email: fortuneferesu@gmail.com Orchid ID: https://orcid.org/0000-0002-2617-555X 6) Nhlanhla Dlamini B.OccTh (UZKN) Community Service Occupational Therapist at Ndwedwe CHC Contact number: 071 298 3216 Email: Ncamisodlamini444@gmail.com 7) Trinity Ncube B.OccTh (UZKN) Contact number: 073 303 6542 Email: Teencube@gmail.com Orchid ID: https://orcid.org/0000-0002-9496-602X 8) Zuleika Patel B.OccTh (UZKN) Community Service Occupational Therapist at Cato Manor CHC Contact number: 076 465 7784 Email: Zuleika.patel@gmail.com Orchid ID: https://orcid.org/0000-0002-9155-2833 Approved by Humanities and Social Sciences Research Ethics Committee (HSSREC) at UKZN (Ref: HSS/0145/019U) Table I: Demographic Table Pseudonyms Age Race Marital status Children Level of education Employment Derek 24 African Single 0 Post graduate Retail Victor 27 African Single 1 Post graduate Porter Thandi 23 African Single 0 Undergraduate Student Vee 23 African Single 0 Undergraduate Student Bob 31 African Single 0 Post graduate Call centre Figure 1: Themes

Abstract Background and Aim The World Federation of Occupational Therapists' urges occupational therapists to recognise when people are being denied the right to participate in occupations and advocate for change. People with oculocutaneous albinism face stigma and discrimination owing to mythical beliefs surrounding the condition. This may negatively affect their engagement in occupations. Therefore, this study aimed to explore the occupational engagement experiences of individuals with oculocutaneous albinism within the eThekwini district. Method A qualitative research design, using a phenomenological approach was chosen to explore the participants lived experiences. Five participants were recruited using snowball sampling. Semi-structured interviews were used to obtain data which was analysed thematically. Results/ Findings Data collected yielded three major themes, sense-of-self, barriers to occupational engagement and facilitators to occupational engagement. Four participants demonstrated a positive self-identity, which supported occupational engagement and aided the individual in overcoming barriers. Reasonable accommodations, social and structural support facilitated occupational engagement, whilst myths and beliefs, physical limitations and the physical environment formed barriers to occupational engagement. Conclusion A new finding that emerged, indicated a change in self-perception, with participants adopting positive self-identities that facilitated occupational engagement. This may be attributed to participants belonging to the millennial generation, which is considered open-minded and deviating from tradition. Key words Albinism, occupational engagement

Introduction: Oculocutaneous albinism (OCA) refers to a group of biologically inherited disorders characterised by a melanin deficiency, which affects pigmentation in the hair, skin and eyes1. Within the South African context, individuals with OCA are considered a minority group who face ongoing discrimination despite constitutional law2. Although South Africa is a country that considers its constitution one of the most progressive in the world; beliefs and attitudes towards albinism are still deep seated within traditional belief systems3. The perceptions of individuals living with OCA stem from a lack of knowledge pertaining to the genetic epidemiology of the condition; these manifests both in self stigma and stigma from the community4. Implications resulting from the overt discrimination and stigma directed at the person living with OCA, such as social isolation and emotional instability, has the potential to directly impact engagement in social activities and daily occupational tasks1. Occupational engagement not only serves to bring meaning and purpose to life, but also contributes to the communities' view of an individual5. This article will explore how having OCA affects the

individuals' ability to participate in their meaningful daily occupations, particularly within the eThekwini district. Literature review OCA is characterized by several physical limitations, such as impaired eyesight and a melanin deficiency which results in a lack of pigment in the hair, skin and eyes. Physical attributes associated with OCA are distinct and unusual owing to the evident white skin tone6. In today's appearance-based society, the way one looks plays a significant role in determining how one is accepted by their community7. These limitations, coupled with the distinct appearance, may predispose individuals with OCA to various barriers which can affect engagement in various meaningful occupations. Myths and beliefs surrounding OCA has great potential to influence societies attitude towards individuals living with OCA, and as a result, may impact their ability to optimally interact within social contexts8. Myths and beliefs can perpetuate the development of societal and self- stigma, wherein individuals accept and internalize the views of other members in society8. The influence of these cultural perceptions is not limited to the development of stigma, as documented by Brilliant9. Cultural practice informs mythical beliefs which have been documented as both positive and negative. Brilliant9 described myths as being the main causal factor of culturally driven traditional practice, murders and mutilations amongst the albino population. However, less documented is the positive mythical interpretations of individuals with OCA, such as in their ability to bring luck to those who come into physical contact with them10. This results in the individual with OCA being held in high regard, protected and endorsed with monetary and material items10. Literature predominantly focuses on the congenital characteristics associated with OCA, as well as the mythical connotations that are underpinned by the physical characteristics6. However, there is limited research exploring the impact these factors have on an individual with OCA and their ability to engage in various areas of occupation. Considering the World Federation of Occupational Therapy's view that engagement in occupation is a human right, rather than a health issue, it is imperative that occupational therapists analyse any potential barriers as well as facilitators to occupational engagement for individuals with oculocutaneous albinism4 . Method: Design: This study used a qualitative study design as the aim was to generate an understanding of the lived occupational engagement experiences of individuals with oculocutaneous albinism using an interpretative phenomenological approach11,12. Ethics: Permission was obtained from the Humanities and Social Science Research Ethics Committee at the University of Kwa-Zulu Natal. Researchers were given the protocol reference number HSS/0145/019U (Annexure 1). Information handouts and informed consent forms were distributed once individuals had voluntarily agreed to participate. At the interview, participants were informed of confidentiality, ethical responsibilities of the researchers, the right to use pseudonyms and the right to withdraw. Informed consent for audio-recording and field notes were obtained using consent forms. Sampling: The study was set in Kwa-Zulu Natal, eThekwini district. Purposive snowball sampling guided selection of participants. Inclusion criteria included a confirmed diagnosis of oculocutaneous albinism, the participant had to be aged between 18-65, and be a resident of eThekwini for at least one year. Data Collection A semi-structured interview schedule was formulated using the occupational justice framework to guide the formation of questions (Annexure 6 & 7). The questions were tested in a pilot study and found to be easily understandable, and yielded sufficient information to answer the research question, however minor adjustments were required. Five individual semi-structured interviews were conducted in English and IsiZulu with a translator. Semi-structured interviews were advantageous as this data collection method allowed for dynamic engagement between the researcher and participant, enabling clarity, understanding and reflection which were vital in establishing an open communication channel12,13. Interviews were audio-recorded with permission from participants, and

field work observations were noted. Interviews were conducted at venues that were convenient for each participant. Data Analysis: Audio-recordings were transcribed verbatim. Braun and Clark's14 thematic analysis was used to analyse data, which allowed for identification, thorough analysis and description of the themes from the data collected. Findings: The demographics of the participants are as below. Two participants were students at a tertiary institute, whilst three were permanently employed. All participants were African and unmarried, with two participants being female and three of the male gender. The data collected revealed three major themes. The first theme described the manner in which the participants viewed themselves, revealing their sense-of-selves. The second theme identified barriers to occupational engagement, whilst the third theme identified facilitators to occupational engagement. These will be outlined below with verbatim quotes to illustrate the themes. Theme 1: Sense-of Self This theme contained two sub-themes namely Identity "I'm just as black as you are", and self- stigma "me and them". Identity "I'm just as black as you are" Findings indicated that participants correlated their acceptance of themselves and their positive self-identity as the reason for their acceptance by society and their communities. "having this personality helps the way people treat me everywhere, not just in the workplace" (Bob, 31, employed) Participants indicated that their positive self-identify developed because of parental acceptance. Moreover, they indicated that extra mural activities promoted the development of a positive self-identity, as well as the establishment of values that promoted positive self- identity. Sense of self culminated in the realisation that acceptance and a positive view of self, originated from the understanding that physical factors were not self-defining, and that identity was based on the portrayal of self. "When you already accept that I'm different, just that my skin colour is different and my needs are a little bit different than the next persons', you can live positively" (Vee, 23, student). Self- Stigma: "Me and Them" Participants spoke of "me and them" as a differentiating concept between themselves and those whom the participants considered as "normal". From the concept of "othering", the participants expressed a sense of self that reflected self-stigmatising views. This was expressed by adopting a self-identity that reflected derogatory terms associated with albinism. The implications of self-stigma predominantly affected the area of social participation. "Those people will not recognise you, because he didn't know or she didn't know the pain that you have, but it's better if you are helped by someone with a disability, because he/she knows the suffering of being disabled". (Victor, 27, employed) Theme two: Barriers to occupational engagement This theme comprised of three subthemes, namely environmental barriers: I like the beach but it doesn't like me, physical limitations: our eyeglasses can't help us much, and myths and beliefs: I am afraid. Environmental Barriers: "I like the beach but it doesn't like me" The findings yielded several environmental barriers which limited engagement in various areas of occupation. Evidence of this surfaced in the participants who were engaged in work. Environmental barriers were not only limited to workplace settings, as participants explained that the intensity of the sun presented as a barrier when engaging in outdoor activities. The implications of the participants' exposure to the intensity of the sun had the potential to limit occupational engagement, as well as the propensity to result in adverse health implications, such as skin cancers. "The only thing that I liked, really liked, was soccer cause I was a bit of a tomboy growing up. But then the sun, so I can't like play at twelve, so it was something I liked doing and couldn't" (Thandi,23, student). "It's easy to be affected or to get cancer when you are not using a body lotion… you must look at the weather… when you see it's 31 degrees today, you must use 50% lotion because that means the sun is high" (Bob, 31, employed). "I never played sports in school, cause of my skin colour... I used to get sun burnt bad" (Thandi, 23, student). "If the weather is 32 degrees I can't say 'guys I will be sunburnt'... normally I

will come back with me sunburnt" (Thandi, 23, student). Physical limitations: "Our eyeglasses can't help us much" Limitations associated with the congenital features of oculocutaneous albinism emerged as barriers to occupational engagement among the participants. Owing to a lack of melanin within their skin and eyes, they experienced physical limitations such as extreme hypersensitivity to light, as well as visual impairments. The limitations specifically affected the participants' performance in areas within places of education, work and pertaining to social participation and leisure. Barriers to scholastic engagement caused by impaired eyesight was emphasized by the lack of accommodations within mainstream schools. However, the university offered reasonable accommodations which served as a facilitator to learning, however this simultaneously acted as a barrier to social participation. For instance, lecture notes were printed and made available to the participant to compensate for her impaired vision; this resulted in hostile sentiments between the participant and her peers, as she was not permitted to share the notes with other learners. "It was in two tutorials that I just didn't know what was going on because the tutor was writing on the board" (Thandi, 23, student). "[The lecturer] He emailed me the slides and told me not to share... I am in class and the slides are open on my laptop… everybody sees I have slides... now I cannot share them [the slides] with them" (Thandi, 23, student). Impaired eyesight also impacted workplace experiences, where two of the three employed participants expressed challenges in performing their worker roles. In addition, participants explained that being sensitive to the sun posed adverse health risks, which directly impacted their engagement in leisure activities and social participation. "you need to be vigilant; you need to see what's happening. You need to pay attention to any transaction when you want to grow, you are required to work the till, my eyesight is bad and the till is fragile, it's very scary. I was going to be seen as a nuisance you know because first of all I can't see clearly there is too much lighting" (Derek, 24, employed). "When you see the lights at the hospital, they are so bright, so we don't deserve to be in the place that is bright, because our eyes get affected" (Victor,27, employed). "When I come from indoors from being in the sun after a while I get a migraine" (Thandi, 23, student). Myths and beliefs: "I am afraid" Myths and beliefs are rooted within traditional beliefs and rituals, and particularly within community settings. The participants shared that they were called derogatory names within a social setting, which was attributed to societies' myths and beliefs surrounding individuals with albinism. Participants expressed that their fear within community settings originated from the association of albinism and traditional rituals, resulting in the development of feelings of vulnerability to harm. Vulnerability emanated from the myth that individuals with albinism bring good luck. This faulty belief was seen as the driver for the fatal repercussions of these beliefs, when people with OCA are murdered, or their body parts used for muti. Further effects extended into intimate relationships, where strangers expressed a desire to engage in sexual activities with three of the participants, due to these mythical beliefs. "There was this mom and this lady was with her kids, three kids, and they were like 'hawu, sawubona umlungu, sawubona umlungu (derogatory name for white person). The mom said, 'ay, it's better they calling you umlungu, they didn't call you isishawa (cursed)" (Vee, 23, student). "I wasn't allowed to go outside on the road especially, I wasn't allowed to travel alone, I had to travel with an adult" (Derek, 24, employed). "Let me make this clear, I'm afraid to go alone, I prefer to go with a person who I have a relationship with, like my friend or my family so that when something happens, I can know who can look after me" (Victor, 27, employed). "when you go outside, people give you money, they say 'ay, please pray for me, you bring good luck' and then that person, that random person just approaches you and gives you money" (Vee, 23, student). "They believe when you are born with albinism, luck is around you. You become rich. So that is why in Central

Africa, people with albinism are being slaughtered and their parts are being sold to sangomas" (Vee, 24, student). "Like people randomly say they wanna sleep with me or stuff you know things like that" (Thandi, 23, student). Theme three: Facilitators to occupational engagement This theme comprised of four subthemes, namely social support: "She took it upon herself to train me while others were… too tired", coping mechanisms: "Escape from the real world", structural support: "Different people need different things" and reasonable accommodations: "I can't read print that is too small or too light". Social Support: "She took it upon herself to train me while others were… too tired" Social support emerged as a common factor that supported four out of the five participants' engagement in occupations. Four participants mentioned the church as an area of occupational engagement, with one participant expressing a strong presence of his church community in his life, as well as a social support network in the workplace. "They are like my second family if I may say, those beliefs, they just check up on me cause you know in the news you hear this and that. They just check up on me. Others even come here and check up on me" (Derek, 24, employed). Even though only one participant specifically named his church community and work colleagues as forms of support, three other participants highlighted the presence of supportive people in their lives as a system that enabled them to engage in occupations. Participants expressed that the relationship and support received from family members facilitated occupational engagement. "I owe her a lot. She is the one who took it upon herself to train me while others were, I don't know. I'm looking for this word, too tired" (Derek, 24, employed). "If I am home or like say if am leaving home my brothers accompany me to the taxi rank so they just leave me in a taxi they know am safe in a taxi what happens that side" (Thandi, 23 student). "Well my father was my major support system, if I may say. Because as I said, he gave me everything I needed whenever I needed so. He, we had plans of after matric I would go varsity and all that stuff so when he passed on its like wow it felt like my whole world just flashed away and I was like wow that it I'm on my own now" (Derek, 24, employed). "Someone that I can talk to with, my mom, then I would definitely go to her. But other than that I would go to my aunt... cuz she's my best friend"(Vee, 23, student). It is evident from the data collected that social support structures are seen to promote and facilitate engagement in all areas of occupation, particularly work and instrumental activities of daily living. Coping Mechanisms: "Escape from the real world" Under this subtheme, the participants exhibited different coping mechanisms to facilitate engagement in social participation. Four of the five participants used music in different forms as a means to cope with social challenges arising from with living with albinism. Two out of the five participants expressed that music was used as a means to cope, and two other participants expressed that music was used as a means to engage in social participation. "The best thing that I had to do to escape from the real world was get involved in some activities, school activities like poetry and music and so forth" (Derek, 24, employed). "I just do music as a hobby, something to take my mind off things" (Bob, 31, employed). "I go to Maskandi Festivals (music festival). I meet up with my friends from Maskandi" (Vee,23, student). In terms of coping with environmental barriers, it was noted that all the participants used protective gear such as sunglasses, long sleeved clothes, hats and sunscreen in order to protect them from the sun's direct glare. "So I normally bring sunglasses, sunscreen and a hat. I try to get something like a cover up so my shoulders, my arms and everything is covered. I also like you know try to get the best sunscreen I can get. Some of us with albinism need an umbrella" (Thandi, 23, student). Structural support: "Different people need different things" Participants indicated the supportive role that established structures played in facilitating occupational engagement. These structures included the disability unit within the university,

technology and media. The disability unit provided two of the participants with access to online lecture notes, allowing for modification of font size through the use of technology. Media served as a platform to promote albinism awareness to the wider public, as well as to advocate for the participants and their individual needs. "I think it was two tutorials that I just didn't know what was going on because the tutor was writing on the board and then I went to the disabilities unit after the second one. I told them and then they emailed the tutor, and then whatever she wrote on the board she later emailed it to me" (Thandi, 23, student). "Maskandi has the second biggest followers in South Africa and those people are the people that are coming from the farm, the same people that believe we are luck. Since Maskandi has such an influence, I asked him [the DJ] to make a song about people with Albinism...He did it and after that a lot of people were like ….'Haibo, people really kill you for muti? and you're like 'Ja'; cos they heard it from the song" (Vee, 23, student). Reasonable accommodations: "I can't read print that is too small or too light" Four of the five participants noted that accommodations made in various educational institutions such as enlarging the font size, providing printed materials, computers with software that catered to their eyesight needs, and lectures being audio taped, facilitated and supported their ability to fully engage in education. "See at school everything was enlarged so we didn't have to wear magnifying glasses so it was just catered for" (Thandi,23, student) "We have like a different LAN [local area network] where our computers like are just adjusted to be where you want it to be" (Thandi,23, student). "Studying was basically online, most lectures were audiotaped" (Bob,31, employed). "I normally took the notes from the teacher and wrote it down after we done writing on the board" (Bob, 31, employed). Discussion A positive sense of self emerged as individuals acknowledged that the way in which they felt about themselves and the way in which they translated this self-perception, was the way in which society perceived them. All participants, except one displayed acceptance towards their condition, and used their positive identity as a catalyst to facilitate occupational engagement. "Me and them" emerged as a differential perception of the self among participants, whose self-perception reflected self-stigma. However, only one participant indicated that his stigmatising view of himself impacted on social participation negatively. Upbringing played a large role in contributing to the development of a positive sense of self, as depicted by the participants who emphasised the development of self-acceptance as originating from parental acceptance. These findings are supported by Christianson, Pooe-Monyemoore and Mavundla15 who emphasized the role of the family in the development of a good self-concept, and ultimately a well established self-esteem. Parental acceptance and support facilitated the participants' engagement in extra-mural activities that instilled fundamental life skills and values, which underpinned their positive sense of self and identity. In contrast to these findings, Wan-Kee- Cheung16 and WHO17 emphasised the direct link between stigma, discrimination and social withdrawal, which negatively affected the individuals' ability to engage in socially orientated activities. An important factor that needed to be noted was the age of the literature, as contemporary articles depicted a positive sense of self, whilst older articles reflected individuals with albinism who were defined by their physical appearance and the associated societal stigmatisation16,17,15. Findings from this study relating to a positive sense of self, was supported by Christianson, Pooe-Moneymoore and Mavundla's15 research, which may be attributed to the attitudes and perceptions of the millennial generation, which is considered open-minded, liberal and deviating from traditional beliefs18. This study found that a positive sense of self culminated in the conclusion that acceptance stemmed from the understanding that physical attributes associated with OCA were not self-defining, and that identity was based on the way in which one conducted oneself. Physical limitations prevailed as one of the key contributing

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challenges to occupational engagement, underpinning environmental barriers and mythological beliefs. Within this study participants confirmed their visual impairments impacted on their performance in various areas of occupation, from childhood to adulthood. Franklin et al19 emphasized the magnitude of the effect of visual impairments on scholastic performance, as students were not given access to the necessary reasonable accommodations within mainstream schools. The release of the Education White Paper 6, which forefronts inclusive education, directly contradicted the individuals' experiences within the mainstream schooling system20. This emphasised the inability of mainstream schools to accommodate for individuals with albinism, despite constitutional law. The occupational Justice frame of reference acknowledges the contribution of policies both international and national to occupational engagement. According to this frame of reference policies can either facilitate or limit participation in occupational engagement. In this study it is noted that White Paper 6 policy was set in place to facilitate occupational engagement and reduce occupational deprivation however, the manner in which the policy has been implemented does not mitigate the barriers arising from physical barriers of albinism. Owing to the challenges attributed to physical barriers in people with albinism, these individuals are placed within "special schools", despite the potential for structural adaptations that would facilitate learning within mainstream schools19. These physical limitations were shown to impact the participants throughout various stages of their life. The workplace was another context in which the participants' physical limitations acted as a barrier. One of the three employed participants was able to perform his work specific role to satisfactory standards, while two participants identified that the workplace environment limited their potential for growth, owing to the lack of reasonable accommodations provided. These findings were supported by Mutasa21 who found that a work environment which is not holistically supportive of the needs of their employees, limits the employees from achieving their maximum potential. Physical limitations included the participants' extreme skin sensitivity to the sun, which was found to have significant occupational implications in the areas of social participation and leisure. This finding was emphasized by Matshovhana and Mulibana22 who stated that the utilization of free time was affected as there was a range of challenges that individuals with this condition encountered while participating in outdoor recreation activities. Despite these challenges, all the participants made attempts to engage in their preferred occupations. Additionally, myths and beliefs have well-established ties with albinism, particular to traditions and rituals within community settings. A lack of knowledge emerged as a concept that underpinned the correlation between the condition and the pervasive mythical beliefs. Myths and beliefs infiltrated into social perceptions of the participants who were called derogatory names when in social and community settings2,8. Participants expressed that their greatest fear was associated with mythical beliefs, which emanated from albinism and traditional rituals. This established fear was particular to interaction within open community spaces, where participants felt most vulnerable, requiring accompaniment from other people. The emergence of vulnerability correlated with the fact that mythical beliefs associated with albinism originated from the belief that individuals with albinism bring good luck. This statement was brought to light by the implications of mythical beliefs and societal interactions from a point of admiration. While the perception of luck appeared to have monetary gain for individuals with albinism, the potentially fatal repercussions associated with these mythical beliefs, such as the killing of individuals with OCA for body parts which are used in traditional medicine, could not be ignored8. Occupational implications associated with myths and beliefs extended into the workplace in the form of stigma and discrimination, in particular to the provision of job opportunities, as perceived by the participants. Participants indicated that job opportunities were limited to learnerships as opposed to permanent

employment, which they perceived as unjust. South Africa implemented the green paper on human resource development as a means of developing the skill set of South Africans who were perceived as disadvantaged, providing them with an opportunity to integrate into the workforce23. Whilst learnerships were perceived as discriminatory from the perception of the participants, legislation indicated that learnerships were in fact an empowerment strategy23. Findings from this study highlighted components of various support systems such as the media, support groups, and the use of technology. Supportive organisations, such as the Albinism Society of South Africa as well as the university's disability unit, were established to facilitate occupational engagement24, however four out of five participants indicated that they did not utilize these organisations as occupational facilitators, but rather as social platforms. One participant identified the organisation as a platform for advocacy, which benefited the participants and other individuals with albinism. This finding is contrary to a study conducted by Mutasa21, in Zimbabwe's Manicaland province, which found that all the respondents in their study sought support for occupational engagement from organisations for people with albinism. In terms of social support, it was found that facilitators to occupational engagement in this context came from friends, work and church colleagues, as well as family members25. Majority of the participants in this study noted that their family gave them comfort and support that helped them fully engage in their occupations. Mutasa21 also found that participants in their study had supportive families who understood their conditions. According to their study, family support as a means of social support was a facilitator to occupational engagement. This echoes the findings of this study, as the majority of the participants expressed that a relationship with family members encouraged and supported safe engagement in occupations21. In the findings from this study, the majority of the participants used sunscreen or protective clothing when taking part in activities that exposed them to direct sunlight. Kagashe, Maregesi and Mnyenye26 also found in their study that people with albinism made use of sunscreen as a means to cope with the effects of the sun on their skin, when they engaged in occupations outdoors which exposed them to the sun's direct glare. This research found that the awareness of the condition, and the effect of the sun on their skin, did not necessarily mean participants avoided the outdoors completely, which was noted in this study, as the majority of the participants found a way to mitigate the effect that the sun had on their skin, as opposed to only staying indoors26. However, in this study participation in outdoor activities was limited to activities of daily living and social participation. Participants verbalised reservations when applying for a job, or engaging in sporting and leisure activities that required them to be in direct sunlight for extended periods of time. Mutasa21 found that the participants in their study used religious affiliation as a coping mechanism, as attending church brought a sense of community. Their study found that religious leaders played a major role in educating the community on albinism, and reducing the stigma and discrimination that people with albinism faced21. In this study, the findings were somewhat surprising, that even though the majority of the participants were members of a religious community, only one participant considered the church as a facilitator to occupational engagement. However, the findings in this study noted that the majority of the participants used music as a coping mechanism, in addition to social support, structural support and reasonable accommodations which could not be refuted or substantiated by literature as there is little to no research on music as a coping mechanism in people with albinism. Conclusion: In conclusion, the findings from this study identified various barriers to occupational engagement which were rooted in congenital characteristics associated with the condition. The congenital characteristics associated with OCA, specifically lack of pigmentation in the hair and skin, were the predominant causal

factor to mythical beliefs. A pivotal finding of this study was the sense of self which emerged as a new finding, to existing literature that found people with OCA tended to be withdrawn and had a negative self-image (Msomi, 2014). A positive sense of self underpinned facilitation in occupation, as participants utilized foundational values developed through parental acceptance and extramural activities. In conjunction with a positive sense of self, social support, structural support and reasonable accommodations facilitated occupational engagement. In the face of barriers to occupation, participants utilized coping mechanisms as a means of facilitating engagement in various areas of occupation. Limitations of the study Limitations of the study included the small sample size, as the study included only five participants. All participants were African race and resided with the eThekwini district. Addressing these limitations in future research would improve the strength of the findings.

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