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Women's experiences of living with albinism in Taiwan and perspectives on reproductive decision making: A qualitative study

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ABSTRACT

People with Albinism tend to face multiple adverse physical, psychological and social consequences. Very little is known about experiences of women with Albinism and their deliberations whilst making reproductive decisions. This study aimed to explore lived experiences of women with Albinism and to understand their perspectives on reproductive decision making. Qualitative in-depth semi-structured interviews were conducted with ten women with Albinism in Taiwan. Five key themes emerged from the accounts which were centred around the sense of discrimination that they felt whilst growing up, their strive for normality, making difficult choices in their reproductive decisions, desire to protect children from harm and reflections of parenting struggles from own experiences and the experiences of their parents. We call for global and national policy makers and practitioners to introduce explicit measures to challenge the myths, stereotypes and prejudices associated with Albinism including specific interventions towards supporting women in pregnancy decision making.

ARTICLE HISTORY

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KEYWORDS

Albinism; experiences; reproduction; women; motherhood

Points of interest

- Very little is known about the lived experiences of women with Albinism and their deliberations whilst making reproductive decisions.
- The research found that a key element of the overall experience is the sense of discrimination that the women had to face due to their physical appearance and visual impairment.

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- Most women actively attempted to fight off notions of abnormality and to keep their identity close to what they perceived as normal.
- The women with and without children viewed pregnancy decisions as making difficult choices. Having a child who would not inherit Albinism was a key influence in pregnancy decisions.
- They strongly desired to protect the children from the difficult experiences that they have had.
- The research recommended that global and national policy makers and practitioners should introduce explicit measures to challenge the myths, stereotypes and prejudices associated with the condition including specific interventions towards supporting women in pregnancy decision making.

Introduction

Albinism is a group of inherited conditions characterised by hypopigmentation of the skin, hair and eyes due to the shortage or absence of melanin production caused by genetic mutations (Carmona-Rivera et al. 2011). There are different types of Albinism; the most common phenotype is the Oculocutaneous Albinism that affects the pigmentation of the skin, hair, and eyes (Brocco 2015). The lack of protective melanin pigment in people with Albinism often results in visual impairments, susceptibility to sunburn, skin cancer and infections in rare cases (Kaplan, De Domenico and Ward 2008; NOAH 2019; Oetting and King 1999). While Albinism occurs worldwide regardless of race, ethnicity or gender, its prevalence tend to vary among regions across the world. Regional or country level prevalence data of Albinism remain sparse, but the condition is indicated to be more prevalent in Sub-Saharan Africa with rates ranging from one in every 5000 to 15000 persons compared to one in 17,000 to 20000 in Europe and North America (NOAH 2019; United Nations 2015). The global prevalence of all known forms of Albinism is approximately 1 in 17,000 (Grønskov et al. 2014).

People with Albinism tend to face multiple adverse physical, psychological and social consequences from not only the apparent manifestation of the disorder on their sight and skin, but also the societal perception of the disease (Arnheiter et al. 2016). Prevailing myths combined with lack of knowledge lead to situations where people with Albinism are harassed, kidnapped, mutilated, and occasionally killed, or their graves vandalised or robbed in some parts of the world (Estrada-Hernandez 2018; Lund 2001; NOAH 2019; Westhoff 1993). An alleged outbreak of killings of people with Albinism in Tanzania's north-west regions roused national and international media debates (Bryceson, Jönsson, and Sherrington 2010; *BBC News*, July 24, 2008). In Uganda, Bradbury-Jones et al. (2018) observed that majority of

people with Albinism underwent life-long, systemic discrimination and violence. Extremely heinous beliefs and myths about the curative properties of the body parts of children with Albinism and their potential usefulness in good luck rituals exist in some parts of the world (Bradbury-Jones et al. 2018; Franklin et al. 2018; UTSS 2018). Researchers have also pointed out that the myths and attitudes towards Albinism held by those without the condition is also being held by those with the condition (Estrada-Hernandez 2018). Various international organizations have called for the prevention of attacks and discrimination against person with Albinism and for creating awareness about the condition among those affected as well as among the general public (United Nations 2014; WHO 2011).

Although interest in the experiences of those affected by Albinism and the factors associated with their adaption has gradually increased over the years, it would appear that most of the research on the experiences of living with Albinism comes from African countries, and very little research has focused on the experiences of women with Albinism and their deliberations whilst making reproductive decisions.

As in many other countries, the prevalence of Albinism is largely unknown in Taiwan and it remains a little known disorder, but it has been indicated that in countries in the region such as Japan and China, the predominant form of Albinism is oculocutaneous albinism (OCA)1 followed by OCA4 (Inagaki et al. 2004; Marçon and Maia 2019; Rooryck et al. 2008). With respect to reproductive choices, childbearing is generally an expected and important part of family life in Taiwanese culture where, women who are unable to have children are at risk of discrimination and high levels of stress related to the need for motherhood (Cheng et al. 2018). However, it has also been indicated that the fertility rate in Taiwan has declined over the years and in 2019, Taiwan had one of the lowest fertility rates in the world (National statistics of Taiwan 2020).

While international organizations have reiterated the sexual and reproductive rights of people with disabilities including their right to marry and have a family (United Nations 2006), the reproductive health needs of women with disability continue to be a neglected area in many countries possibly due to the notion that women with disability are not sexually active and are not desirous of having children (Groce and Trasi 2004; Kallianes and Rubenfeld 1997; Mia 2020). A qualitative study that explored the attitudes and behaviours in rural Nepalese society towards women with disabilities, their pregnancy, childbirth and motherhood reported negative societal attitudes with misconceptions about disability based on stereotypes and a prejudiced social environment. The participants reported anxieties and fears that a disabled woman's impairment would be transmitted to her baby regardless of the nature of the impairment, and often viewed pregnancy and childbirth of women with disabilities as an additional burden for the family and society

(Devkota, Kett, and Groce 2019). Other researchers have reported traditionally widespread beliefs that disability severely limits the ability to satisfactory parenting that could potentially lead to issues of maladjustment in children (Buck and Hohmann 1981; Kirshbaum and Olkin 2002). It would also appear that the research literature on mothers with disabilities have failed to consider differences with respect to the levels of functioning in various disabilities.

No previous studies have explored the lived experiences of women with Albinism or their reproductive health needs in Taiwan and other countries in the region. The aim of this study was to fill this evidence gap by exploring the lived experiences of women with Albinism in Taiwan and to understand their perspectives on reproductive decision making.

Methods

We conducted a qualitative study using in-depth semi-structured interviews among women with Albinism in Taiwan. We adopted a descriptive phenomenological approach as very little previous research existed in this area and the aim was to discover the meaning of subjective experiences (Husserl 1962; Polit, Beck, and Hungler 2001). The data were collected from August 2018 to November 2018. Purposive and snow-ball sampling methods were used to recruit participants. We recruited the first two participants through the membership of an occupational union for the visually impaired that protects the common interest of workers, the Tainan Visual Impaired Massage Therapists Union. We chose this organization as a potential channel for recruitment as Albinism often results in visual impairments of varying severity, and the most common occupation for those with a visual impairment in Taiwan are as massage therapists (Li 2001). Most people who have albinism with visual impairment work as massage therapists. Taiwan's government provide vocational training for persons with visual impairment and provide information and assistance in joining local occupational unions.

These participants introduced women who met the study's inclusion criteria and an additional eight participants were recruited through snowballing. The inclusion criteria for participation were that the women had Albinism; they were aged over 18 years; they could listen, speak, read, and write Mandarin, and they agreed to be interviewed for the study. The study subjects were mainly from cities of Hualien, Taipei, Taichung, Changhua, Chiayi, Tainan and Kaohsiung. Ethics approval for the study was obtained from the human research ethics committee of National Cheng Kung University, Taiwan (Approval No. NCKU HREC-E-107-108-2).

Ten women took part in the study. The characteristics of the participants are presented in Table 1. Their ages ranged from 20 to 51 years

Table 1. The characteristics of the participants.

Participant	Age	Marital status	Number of family members with albinism	Number of children	Level of education	Occupation	Vision status
A	51	married	1	2	University	Massage Therapist	impaired
B	49	married	2	1	Vocational high school	Massage Therapist	impaired
C	51	widowed	2	0	Vocational high school	Massage Therapist	impaired
D	50	married	1	0	Vocational high school	Clerical	impaired
E	56	unmarried	2	0	High school	Massage Therapist	impaired
F	30	married	2	0	University	Food & Beverage	myopic
G	45	unmarried	1	0	Elementary school	Actor	impaired
H	20	unmarried	1	0	University	Student	impaired
I	28	unmarried	2	0	University	Massage Therapist	impaired
J	34	unmarried	1	0	University	Clerical	impaired

with great majority aged more than 40 years. Half of the women were married including one who was widowed. Two women had children. Half of the women had university level education, three had vocational high school qualifications, one had high school qualification and one had elementary school qualification. All women, except one who was in education, were employed.

The author (MZH) conducted all of the interviews at a mutually convenient prearranged time using a flexible topic guide. The topic guide included questions designed both for women with children and those without. All participants were asked about their perceptions of Albinism, the experiences of living with the condition including their family's reactions to the illness, the feelings about fertility and what influenced their decision to have or not to have children, the response from the partner and other family members, and the internal and external sources of support they had in making their reproductive choices. The women with children were asked about their experiences of pregnancy, the experiences of being a parent with Albinism and any concerns about their baby's health.

The interviews were conducted at the women's homes or another place chosen by them such as a meeting room or a coffee shop at a mutually convenient prearranged time. There was no one else present apart from the researcher and the participant during the interview. The average length of the interview was between 1–2 h. The researcher gave the interviewees time to think about and reflect upon their experiences before the start of the interviews and assured the participants that anything they said would be valued, respected and kept confidential.

All of the recorded interviews were transcribed. The interviewees were given the opportunity to confirm the transcript contents and the analysis was conducted based on Colaizzi's strategy (Morrow, Rodriguez, and King, 2015). First the researchers read the interview transcripts several times and extracted significant statements and phrases which were coded and the codes were grouped into more abstract levels of codes or themes. The analysis was done manually. The first author took the lead in data analysis with the other authors regularly checking for accuracy and consistency.

Results

Five key themes emerged from the women's accounts including their deliberations whilst making reproductive decisions: sense of discrimination, striving for normality, making difficult choices, desire to protect children from harm, and the struggles for parents. The following sections examine these themes in detail supplemented by excerpts from the interviews.

Sense of discrimination

A key element of the discourse was the sense of discrimination that the women had to face right from childhood due to their physical appearance and visual impairment especially in school and at home. Participant J recounted her childhood experiences of being treated negatively by other children and their parents: *'They'd ask, "So what kind of person are you," and "Are you a person?" Kids didn't like playing with me ... They said I was different from them. They made nicknames for me, like Whitey and White-haired Witch, made fun of my looks and hurt me a lot'*. For Participant F, the visible difference in her hair color was a source of discrimination. She stated, *'we had hair rules when I was in school, and my brown-colored hair stood out like a sore thumb. There was no way that I could explain the reason for my hair color to everyone, and it was impossible that everyone would understand.'* For another participant, the leniency shown by the teacher because of her 'difference' was a reason to receive abuse including being 'chased' and 'hit with brooms.' Explicit discrimination from relatives and members of the wider family were also apparent in the accounts with frequently found perceptions such as *'I believe that I wasn't a welcome addition to the family'*. As remarked by participant C who had an older sister with Albinism, *'mom and dad feel that we are an embarrassment to them. Once at church, the pastor called me over and told me that someone in our family had put a death curse on me.'* Participant I stated, *'once when Mom took us on an outing, we saw our grandmother on the same bus. We kept calling out to her, "Grandma! Grandma!", but she moved away from us quickly. She wasn't willing to acknowledge her grandkids in public.'*

Another participant described how she was spurned and abandoned a number of times by adopted parents because of myths surrounding Albinism. She said, *'my adopted mother's mother-in-law got the idea that I was the result of a secret affair ... The family situation went sour and my step-mom could no longer take care of me.'* Participant G's accounts showed her strong feelings of being given up by her parents. She said, *'they dropped me at the nanny's and didn't come back. I was like a football, getting kicked from one place to another. ... If my parents didn't want me, so be it! If they disdain me, so be it! I'm doing fine without my parents (crying).'*

While many participants perceived discrimination from extended family members, this was not always the case. Participant D noted that, *'my uncle and aunt dote over me and I share a surprisingly good relationship with my brothers and sisters.'*

Most of the participants recognized that the greatest impact of Albinism was during their childhood years. As participant D said: *that's [childhood] when you have to get used to your eye troubles and when you have to accept that you are different from other people.'* An associated concern was about

their vulnerability to ailments from the condition evident in accounts such as *'I worry that my skin may become cancerous too'* along with a recognition that they *'need to take especially good care of my skin and eyes.'*

Striving for normality

All the women perceived how the limitations imposed by their physical appearance affected their ability to integrate with others in their family as well as the wider society and how it compromised their ability to see themselves as normal. Most participants actively attempted to fight off the notions of abnormality attributed to their hair or skin color and to keep their identity close to what they perceived as normal. Often there were positive affirmations such as *'there is nothing really wrong with us. It's just that our eyes and skin are different ... that's all! We're the same as normal people.'* Most participants recognized that it was hard for them to accept the idea of *'being different'* initially, but having gone through a *'self-acceptance stage'*, they were able to assimilate their difference better although it never went away completely. For example, Participant H stated, *'my initial unacceptance came from me being different. After going through the self-acceptance stage, I could accept it [Albinism].'* Often there were notions such as, *'I have no choice but to accept the way I am.'* This also involved trying actively to find positives about aspects of their physical appearance. Participant B said, *'when I was young, some would say how great it was to have it this way (blonde hair) without having to dye it. But I'd still rather have the experience of having black hair and letting it gradually go white.'* More or less similar views were expressed by Participant E: *'You need to find the blessings within your shortcomings. I often think that God loves me especially much because he gave me such a natural look. I try hard to not look like a blind person.'*

There were explicit efforts to fight off social perceptions while preserving aspects of physical appearance as part of their identity. Participant A mentioned, *'before my wedding, Grandma asked me to dye my hair. But I wouldn't be me if I did that. I don't even know myself. Why would I dye my hair?'* There were also accounts of how they tried to separate themselves from others with Albinism in an effort to see themselves as normal. Participant J explained that her refusal to interact with other people who are affected by Albinism was mainly because she had *'no interest in seeing others like me (with Albinism) on a regular basis, which would just remind me that I'm different.'* Another Participant described her family's explicit disapproval of social interactions with those affected as she recounted the experience of bringing home a friend with Albinism: *'the first time I brought a friend with Albinism home with me, it was clearly a shock to everyone. Mom asked me whether it was my intention to make the neighbors think that our whole family had albinism?'* (Participant C)

Making difficult choices

The participants with and without children viewed their pregnancy decision making as making difficult choices. A key consideration that guided their reproductive decision making was a strong desire to have a child who does not inherit Albinism. Consistent with their own perceptions of being deviant, all participants were unanimous in the importance that they accrued having a child who would not inherit Albinism although there was a recognition that it was more like *'being abnormal'* with hopes of having *'normal'* children. Participant A whose child did not inherit Albinism, mentioned, *'I was so happy my child hadn't inherited (my Albinism).'* There were accounts of resorting to all possible measures including undertaking preimplantation genetic diagnosis (PGD) to ensure that their children were free of Albinism and to end the genetic transmission of the condition. As stated by participant F, *'unless a surprise, I would make every effort to avoid giving birth to a child affected by Albinism ... Before getting pregnant, I would ask my husband to get checked for the Albinism gene. If he is a carrier, we would go in for a preimplantation genetic diagnosis (PGD) to select a healthy embryo.'* A concrete decision to end the pregnancy in case Albinism was detected in the fetus was also evident in the accounts. Participant J said, *'it's hard to say ... If the fetus had Albinism, I wouldn't see the pregnancy to term ... I wouldn't want my child to undergo the hardships of growing up like I have.'*

Although not often, there were instances of participants reporting the pressure that they experienced from the family against pregnancy as reported by Participant C, *'my father forced me to have an abortion. He said my husband and I had no right to have a child because of our financial situation and because of my Albinism. He forbade us to have children.'*

The joy of confirming an Albinism-free fetus was evident in the accounts of the two participants with children. Both of them underwent diagnostic tests to get it confirmed during their pregnancy. Participant A recounted her experiences of going through prenatal testing, *'I was very concerned that my child would inherit my Albinism, so during pregnancy, I asked for and underwent an amniocentesis ... I remember a long delay between the amniocentesis and when I received the report. I was so worried and nervous ... all the way up until I finally got the report saying I had a 'normal male' child. Only then could I set my fears to rest. Boy or girl, it wasn't so important. 'Normal' was the important word. I was so happy my child hadn't inherited (my albinism).'* Participant B reported about how the worries about having an Albinism free child were shared by her husband: *'only after our child was born did my husband confide to me that he was worried and anxious as well. He felt that having a baby should be a good thing. He didn't want our child to have Albinism like me. I was so fortunate to have given birth to a child who is different than me.'*

Desire to protect children from harm

Another key influence in their reproductive decision making was the desire to keep their child/children away from harm and to protect them from the difficult experiences that they had while growing up. As remarked by Participant B, *'I wouldn't want my child following the difficult road I had to take growing up.'* The prejudice that they experienced was a key factor that prompted their desire to have an Albinism free child. Participant F stated, *'since I was little, I've experienced prejudice and sideways glances. More than anyone else, I hope that my child would be the same as everyone else.'* The experience of discrimination was also a strong deterrent for some participants to decide against having children as implied in the account of Participant D *'... having a child like me [with Albinism] ... I'm not one to insist on having children, because I wouldn't want to make a child go through what I have experienced.'*

There were explicit concerns such as *'however much parents protect their child; it is never enough to keep him or her from harm'* and *'it would be a hardship for the child as well as for the parents.'* Alongside the recognition that parents should be able to provide the *'child with a good environment for the remainder of their life'* participants mentioned their compromised physical ability as a deterrent in their decision to have children. Participant E stated, *'being in good shape financially, doesn't mean that you will be [able to take care of the child] ... I won't get married or have kids because my vision is poor.'*

Struggles for parents

The accounts from participants reflected their own struggles of being a parent with Albinism as well as witnessing the struggles that their parents experienced as a result of having a child with Albinism. The two participants with children tended to hoard feelings of guilt due to themselves being different to other mothers. Participant A stated, *'I've told my children since they were very young that fate made me their mother and that I am sorry for it being this way. I tell them that they should never argue or quarrel with others because of the way I look.'* The same participant noted how she was often mistaken as a grandmother during drop-off and pickup times at her kids' school.

Strong feelings about the struggles that their parents experienced as a result of having a child with Albinism were evident in some accounts. Participant I stated, *'my oldest sister has Albinism and my mom said she had hoped that her second child would be normal (not affected by Albinism). When I was born and the doctor told her that I also had Albinism, mom said that her only thought was to die because she felt she'd be unable to cope with the pressures of raising two abnormal children.'* The participants recounted the

disappointment, embarrassment and the strong emotional turmoil that their parents experienced while bringing up a child with Albinism. Participant C said, *'dad always gets angry when others get too nosy or intrusive toward us. He is unable to accept that his own child has Albinism. He sees it (Albinism) as shameful ... even feels that he can never again be hopeful or self-confident ... Dad doesn't allow us to stay outside after school because the neighbors will get nosy and intrusive.'* Perceptions about feelings of guilt experienced by parents was also evident in some of the accounts. Participant D stated, *'my family is apologetic, and takes special care of me.'*

All the participants acknowledged the struggles of their parents while bringing up a child with Albinism. Participant G stated, *'it's hard for me, and I believe it is very hard on my parents as well. They didn't know how to educate me, so they gave up on me.'* There was also an expressed dissatisfaction in some accounts about their own helplessness in mitigating the issues faced by parents. Participant E stated, *'my parents just can't accept that they gave birth to a child that is different. Of course, I think, 'Do you think I wanted to be this way? ... Should it be an embarrassment to have a handicap?' But in their eyes, it is an embarrassment. But we can't choose (how we are).'*

Other participants described how they felt constantly over protected by their parents and other family members while growing up. Participant A stated, *'my younger sister is quite protective of me. When you see me, you're sure to see her too. My family never lets me go out alone.'* At times, the over-protection resulted in encouraging exclusionary practices resulting in restricting personal and social relationships. Participant I said, *'when I was young, my parents told me I could date, but, they said, 'if his parents don't like you, then end it there. It won't have a happy ending.'*

Discussion

The aim of our study was to explore women's experiences of living with Albinism in Taiwan and their perspectives around reproductive decision making. The study was conducted among participants who were recruited mainly through a professional association and was based on the experiences of a sample of ten participants. Despite the small sample, the in-depth qualitative methodological approach facilitated the participants to freely express their experiences and perspectives. As few studies have focused on women's experiences of living with Albinism and the deliberations around their reproductive decision making, we have drawn on the wider literature about people's experiences of living Albinism as well as the literature on fertility and disability to compare and contrast our findings.

The key themes reflected in the women's voices were: the sense of discrimination, striving for normality, making difficult choices, desire to protect

children from harm, and struggles for parents. While Albinism can undoubtedly compromise the physical, psychological and social functioning and the overall quality of life, the themes highlighted the range of vulnerabilities faced by women with Albinism and revealed a number of unique stressors faced by them while making reproductive choices. Research has consistently shown the stigma and discrimination faced by people with Albinism and its potential impact on the physical, psychological and social well-being of those affected by the condition and their family members (Arnheiter et al. 2016; Bryceson, Jönsson, and Sherrington 2010; Doris 2019; Estrada-Hernández and Harper 2007; Lund 2001; NOAH 2019; Ntetema 2008; Westhoff 1993). Feelings of disappointment, low self-esteem, hopelessness, anger, and resentment were strongly evident in the accounts of the participants. Similar to findings reported by other researchers, the participants in our study perceived that the greatest impact of Albinism was during childhood (Bradbury-Jones et al. 2018). While identity is a key influence in personal adaptation, our findings clearly showed how self-identity was limited by Albinism and how it affected the women's day-to-day life experiences. Similar to findings reported by other researchers, the participants in our study adopted various coping mechanisms to fight off the notions of abnormality attributed to their hair or skin color (Estrada-Hernández and Harper 2007; Harper 1999; Wan 2003).

A key purpose of our study was to enhance the understanding of the deliberations of these women while making reproductive decisions. It would appear that the overriding concern while making reproductive choices is the desire to have a child who would not inherit the condition. This in turn points to the need for health care professionals to have open discussions about the potential risks offering appropriate forms of support including the options to have prenatal diagnostic testing in a sensitive and caring manner taking a woman-centred approach. Previous studies have noted widespread fears about the baby's risk of inheriting the disability with disabled women being often urged to undergo screening to detect any anomalies (Kent 2000; Walsh-Gallagher, Sinclair, and Mc Conkey 2012). Women's decision to pursue or decline prenatal screening is most likely to be shaped and situated within their personal and social context of disability.

Women with disabilities tended to encounter negative attitudes relating to their pregnancy from different facets including their own families (Iezzoni et al. 2015; Prunty et al. 2008; Smeltzer et al. 2016). Researchers have reported 'mixed messages' voiced by women with disabilities as the cultural value placed on motherhood encouraged a desire for children, but this desire was often tempered by messages of disability-stigma reflecting inability to perform motherly duties both in biological terms of fertility and social terms parenting (LaPierre, Zimmerman, and Hall 2017; Walsh 2014).

For example, a study from Ireland exploring the ambiguity of disabled women's experiences of pregnancy, childbirth and motherhood reported that women themselves welcomed the pregnancy as an affirmation of their identity and worth as women and as mothers. However, they encountered mixed reactions from partners and families which intensified their fears (LaPierre, Zimmerman, and Hall 2017; Walsh 2014; Walsh-Gallagher, Sinclair, and Mc Conkey 2012)

Prominent in the reproductive decision making of our participants was the underlying desire to keep their child/children away from harm. There seems to be very little systematically derived evidence about the parenting needs of those with Albinism or those who have a child with the condition. The most common parental needs whilst caring for a child with a rare disease is the need for information about their child's disease, and appropriate support to deal with potential emotional distress, guilt and uncertainty associated with their child's future health care needs, and parents own caring responsibilities (Pelentsov, Laws, and Esterman 2015). Only two out of ten women in our study had had children. Although no other published studies are conducted in Taiwan about the parenting decisions of women with disabilities, research from other countries have reported inconsistent findings. While some researchers have found that disabled women welcomed their pregnancy as an affirmation of their identity and worth as women and as mothers (Walsh-Gallagher, Sinclair, and Mc Conkey 2012), others have reported that disabled women are significantly less willing to become mothers compared with women without disabilities who have not taken up family roles (Parchomiuk 2014)

This is one of the very few qualitative studies that have explored women's experiences of living with Albinism and their perspectives on reproductive decision making. While the qualitative approach offered the opportunity for an in-depth exploration of the experiences, the study has certain limitations including the limited sample size and the purposive sampling approaches. The participants were mainly recruited through the membership of a professional support group and might over represent the experiences of women engaged with a support group. While the qualitative design allowed for the exploration of the deliberations of the women while making pregnancy decisions, the experiences may have reflected the views of older women and who had decided against pregnancy as great majority of the participants did not have children. The relatively small sample size did not allow us to observe clear patterns with respect to the key themes emerged or to explore the relative importance of the various contextual factors in their decision making. However, regular discussions within the research team and the validation of the accuracy of the preliminary findings by participants would have enhanced the reliability of the results.

Conclusion

The key themes reflected in our study provide insights into women's experiences of living with Albinism and the vulnerabilities faced by them while making reproductive decisions. While the experiences and perspectives are shaped by a range of individual psychosocial and the wider socio economic factors, the findings offer useful information for policy, practice and future research in this area. Global and national policy makers and practitioners should consider the stigma and discrimination faced people living with Albinism and introduce explicit measures, including appropriate legislative measures supplemented by sensitisation and awareness programmes to challenge the myths, stereotypes and prejudices associated with the condition. Gender related stereotypes could make women and girls particularly vulnerable and our findings offer pointers for interventions not only at individual and familial levels, but the wider socio-cultural and the environmental contexts to better support these women towards enhancing their self-esteem as well as their coping strategies. In many cultures, the role of women is seen closely associated with motherhood, and supporting women in their pregnancy decision making is of paramount importance. The psycho-social and informational support needs of parents is another area that needs attention, including support from, and access to trained professionals such as Psychologists and Social Workers.

Given the sparsity of studies on the experiences and perspectives of women with Albinism, good quality quantitative and qualitative studies, in particular using longitudinal and mixed method designs, are needed to provide evidence to inform development of services and interventions to offer support women with Albinism. The support needs of parents who have Albinism themselves as well as those with children affected by the condition are worth exploration. Studies should also aim to develop the components of interventions to support not only those with the condition, but also the parents and the family members.

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The interview transcripts are confidential and therefore not publicly available.

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