



Surveying the Experiences of People with Albinism in Iran: Qualitative Research

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Abstract

Background: Oculocutaneous albinism (OCA) is a genetic disease that causes the impaired conversion of melanin, thus leading to the development of vision impairment and skin/hair-related complications. This disease can also cause extensive psychosocial consequences for patients with this disease.

Objectives: This research aimed to provide a deep understanding of the lived experience of people with albinism (PWA) in Iran.

Methods: This research has been conducted using a qualitative approach. The sampling was done as purposive and continued until reaching data saturation. The data were collected through deep semi-structured interviews, and then analyzed via thematic analysis, after transcribing the interviews and removing the similar codes, 1077 initial codes were extracted. The categories were coded using open coding indirect process alongside several times of reading the text and allocating relevant codes through constant comparison of codes with each other.

Results: The results obtained from data analysis led to extraction of three main themes including: (1) challenges; (2) perceived sources of support; and (3) psychological mechanisms of coping with challenges.

Conclusions: Based on the findings of this research, the main challenges of PWA were categorized into two major groups: Body-based challenges and psychosocial challenges. The perceived support sources of these people against these challenges were social supports and access to facilitator tools. The psychological mechanisms were divided into adaptive and maladaptive sub-categories. The findings of this research can provide a deeper understanding of the needs of these people for providing optimal care and ultimately promote their psychosocial well-being and also can be employed in developing interpretive theories about the biopsychosocial conditions of PWA.

Keywords: Albinism, Lived Experience, Qualitative

1. Background

Albinism has been derived from the Latin term *albus*, meaning white. Oculocutaneous albinism (OCA) is a group of four autosomal recessive disorders, which develops in response to complete absence or diminished biosynthesis of melanin in melanocytes and hence hypopigmentation of hair, skin, and eyes (1). Melanin is a pigmentation which protects the skin against ultraviolet radiation, and also contributes to pigment generation (2).

Albinism begins from the childbirth and continues until death. In case both parents are afflicted or carry the albinism gene, most probably they would transfer it to their offspring (3). This genetic disease causes development of problems and deficiencies related to vision such as

decreased visual acuity, nystagmus, strabismus, and photophobia (4). The prevalence of albinism in the world is 1:20,000. Its prevalence is high in some regions such as East Africa as well as regions of Panama and Columbia, but in the US, its prevalence is low (5, 6). No official statistics exist regarding the number of patients with albinism in Iran, though according to estimations, the population of these people in Iran varies between 5,000 and 35,000.

The World Health Organization defines disability as an umbrella concept which includes damages, activity constraints, and participatory constraints (7). However, whether albinism can be categorized as a kind of disability is controversial. Indeed, the individuals with albinism who have normal occupational activity with no assistance

should not be categorized as disabled. However, in many countries, people with albinism (PWA) who have severe visual defects are legally categorized as disabled (2). These individuals experience more challenges and discriminations compared to their peers from their childhood. In social contexts, they also suffer from various academic challenges, rejection, stigma, as well as numerous physical misbehavior (8). Some researchers have reported the prevalence of experiences of rejection, stigma, discrimination, injustice, prejudice, ridicule, blame, and even physical abuse among people with albinism (9-11). In addition, PWA also experience challenging conditions with regards to the family, teachers, peers, and friends because of the direct and indirect constraints caused by albinism. Presenting a direct understanding of the experiences and conditions of PWA helps families and teachers as well as those dealing with this population experience harm-free and healthier relationship with these people. Various qualitative research has been performed on the lived experience of PWA in different countries especially continental Africa. Since generally PWA have pale skin and hair, these stark apparent differences (paleness or whiteness) among the majority of blacks in some of these African countries as well as the prejudices along with superstitions related to albinism have subjected them to special crises and risks such as homicide and mutilation. The major focus of the research literature in these countries has been about these violence, stigma, and community-based discrimination (12, 13). These studies have not been successful in providing experiences and perceptions as well as the psychological mechanisms of PWA against challenges. The lack of familiarity of people without albinism with the conditions and challenges of PWA in social situations such as school, university, and work environments can worsen their conditions and sometimes cause them to be isolated and avoided. Therefore, identifying the major challenges of these people can help improve healthy interactions and reduce communication conflicts. Meanwhile, the present study was planned and implemented since (1) the extent of apparent difference of Iranian PWA is not as severe as that of PWA in African countries (14); (2) severe violence such as physical harm and superstition-based murders are not common among Iranian PWA (14); (3) so far no research has been performed on examining the psychosocial experiences of this population in Iran; and (4) it is important to know and extract the lived experiences and employ them in interpreting the biopsychosocial conditions of these people as well as develop psychosocial rehabilitation specifically designed for supporting this population.

2. Objectives

This research aimed to provide a deep understanding of the lived experience of PWA in Iran.

3. Methods

3.1. Design

The research was carried out in Tehran, Iran's capital. For organizing the lived experience data of patients with albinism, we used qualitative research approach. Qualitative researches can provide researchers with deep insights about perceiving individuals' experiences. This method focuses on the life experience, as well as interpretation and concepts the patients have been subjected to. Thematic analysis is a qualitative approach of coding and classification used for exploring through large amounts of textual information to determine the trend and patterns of words along with their frequency, interrelationships, structures, and communication discourses (15, 16).

3.2. Participants

Thirteen participants (9 males and 4 females) of this study after introduction of the Iranian Albinism Association (AMAL) were chosen from among PWAs in Tehran via purposive sampling method from those who met four inclusion criteria: (1) having albinism; (2) age at least 18 years; (3) willingness to participate in the research; and (4) not having other debilitating comorbidities (such as autism or multiple sclerosis). The interviews were done as face-to-face and continued until reaching data saturation, i.e., until the 13th interview. According to the conditions and comfort of the patients, 8 interviews were conducted at the University of Social Welfare and Rehabilitation Sciences, and 5 interviews were conducted at the workplace of the patients.

3.3. Data Collection and Analysis

The data were collected through semi-structured interviews from April 2020 to February 2021. The duration of interviews varied from 40 to 60 min, and all interviews were done by the first author T. A. The semi-structured interview includes items that would encourage participants provide rich and profound information about their experiences, perceptions, and views for researcher freely and voluntarily. Also, if required, the researcher established the required flexibility for resolving ambiguities and reaching more profound information through probing questions. Some of the questions of interviews were as follows: "What are your experiences of living with albinism?", "What have been the problems you have experienced in life because

of albinism?”, “What factors have helped you in overcoming the problems caused by albinism?”. Thematic analysis method was used for data analysis. Data analysis was performed using the stages proposed by Braun and Clarke (17). For data analysis, these six steps were taken: (1) first to obtain a general understanding and get familiar with the data, the text of interviews was first transcribed and made anonymous. Next, it was read by three researchers (T. A., B. B., M. S. K.) several times; (2) all interviews were divided into semantic units by one researcher (T. A.), and once summarized, they were labeled with codes. At this stage, 1077 initial codes were identified; (3) after constant comparison as well as based on similarities and relatedness, the extracted codes were assigned into main themes by two researchers (T. A., B. B.); (4) in order to examine whether the extracted codes regarding themes and the entire data set would work or not, a thematic map was created from the analysis by all researchers; (5) in order to correct the features of each theme as well as the general story, and create clear definitions and names for each theme, constant analysis was done by all authors; (6) in the last stage of analysis, the extracted themes were chosen in a vivid, compelling way for the last time by all researchers of the study. The final analysis of the extracted codes was then finalized, analysis was linked to the research literature and question, and a scientific report was prepared from the analysis.

3.4. Ethical Considerations

Ethical approval for the current study was obtained from committee of the University of Social Welfare and Rehabilitation Sciences (IR.USWR.REC.1399.017). Written informed consent was obtained from all participants to participate in the research. The participants were fully aware of the objectives of the research, the concealment of their identity information and the purpose of using the audio recording.

3.5. Data Trustworthiness Criteria

In order to confirm the trustworthiness of data, Guba and Lincoln criteria were used including credibility, confirmability, dependability, and transferability (18). For credibility of the results, the data were reviewed and confirmed by three qualitative research experts. In order to enhance the validity of the findings, maximum diversity sampling method was used. In order to observe the confirmability principle, the research group did not allow their ideological and personal values affect the course of analysis and extraction of results, and all codes and themes would be re-examined and confirmed with supervisor supervision. In order to take care of dependability, the data were recorded by two members of the research group separately whereby a great consensus was achieved. Finally,

to respect the principle of transferability, the data were reviewed and confirmed by three specialists of qualitative research who did not participate in the research process before this stage. Also, the research results were presented to two individuals with albinism who did not participate in the previous stages of the research; they judged and confirmed the similarity of the research results against their own experiences.

4. Results

Thirteen people with albinism (9 males and 4 females) participated in this research. Further details of the participants are reported in [Table 1](#).

Table 1. Demographic Characteristics of Participants

Variables	Values
Age	
Range	19 - 51
Mean	29.8
Marital status	
Married	2
Single	11
Employment status	
Employed	10
Student	3
Gender	
Males	9
Females	4

The results obtained from analyzing the lived experience data of PWA included three main themes: (1) challenges; (2) perceived sources of support; and (3) psychological mechanisms of coping with challenges. These main themes were divided into primary and secondary categories which are described further. In order to clarify the findings, quotations have been used along with the relevant participant number ([Box 1](#)).

4.1. Challenges

Challenges refer to psychosocial and physical defects, problems, and traumas threatening the physical and psychological well-being of PWA. These factors are defined as two sub-themes of (1) body-based challenges and (2) psychosocial challenges.

Box 1. Thematic Analysis

Themes and Sub-themes
Challenges
Body based challenges
Psychological and physical distresses caused by vision damages
Psychological and physical distresses caused by hair and skin damage
Psychosocial challenges
Resenting others
Prejudice and unawareness of others
Stigma and ridicule
Excessive support and pity
Sense of being rejected and neglected
Challenges associated with emotional relationships and marriage
Constraints in selection and persistence of job
Perceived sources of support
Social supports
Sibling (s) with albinism
Supportive family
Supportive friends and teachers
Access to facilitator tools
Psychological mechanisms of coping with challenges
Adaptive psychological mechanisms
Forgiveness
Anticipation and preparation
Attempt for success
Relationship-seeking and empathy with peers
Psychological mindedness
Maladaptive psychological mechanisms
Projection
Acting-out
Self-attack
Avoidance and helplessness
Lack of assertiveness

4.1.1. Body-based Challenges

The problems and challenges in PWA with a body base and source can cause considerable psychological and physical distresses for these people. These body-based psychological distresses can be explained into two subcategories:

4.1.1.1. Psychological and Physical Distresses Caused by Vision Damages

One of the most important challenges related to PWA is the psychological and physical distresses caused by vi-

sual impairment. Vision problems in this population, as a major stressor, can make the person vulnerable to some psychological challenges, and breed the ground for abnormal anxiety associated with the living environment. For example, participant 2 stated that: "Due to weak vision, I had considerable anxiety in my life. Even now that I am a teacher, every year with the beginning of the academic season, since my vision is weak and I get familiar the environment with delay, I find much anxiety, my heart races, and any moment I fear a possible bad event."

4.1.1.2. Psychological and Physical Distresses Caused by Hair and Skin Damage

People with albinism, because of photosensitivity, have many constraints for activity along the day in outdoor environments. This constraint can impair the fulfillment of some psychosocial needs such as social participation as well as group games with peers, whereby the person may experience sense of isolation and sorrow because of impossibility of accompanying their peers. Participant 5 in this regard states that: "The school sports involved balls, and my eyes and skin were very disturbed under sunlight, and I could neither use sunglasses." In addition to the body-based challenges, these people also experienced psychosocial challenges which are explained further.

4.1.2. Psychosocial Challenges Resenting Others

Psychosocial challenges consisted of three secondary categories of resenting others, challenges associated with emotional relationships and marriage, as well as constraints in job selection and persistence.

4.1.2.1. Resenting Others

This category included unawareness and prejudice of others, stigma/ridicule, sense of pity/excessive support, and being neglected/sense of rejection, which are explained further.

4.1.2.1.1. Prejudice and Unawareness of Others

Presence of prejudices and lack of proper awareness about albinism can lead to behaviors such as staring at person, curiosity, and unsuitable questions posed by people, which were distressful and damaging for PWA. In this regard, participant 5 stated that: "... People ask me about albinism, or I remember when two people talked to each other, they pointed at me why he's in this way, or for example they asked my parents why he's in this way."

4.1.2.1.2. Stigma and Ridicule

Assigning humiliating labels and stigmas was one of the difficult experiences experienced by PWA due to their

albinism. The interaction of these factors sometimes created conditions causing others to underestimate that person's competence. Participant 8 in this regard stated that: "I have tolerated many disasters. For example, during elementary years, they addressed me as an elderly, and in the class, there was a girl who (due to albinism) was afraid of me."

4.1.2.1.3. Sense of Being Rejected and Neglected

These individuals reported many experiences of sense of being neglected and rejected in the society. Many peers did not include them in their games or gatherings, and the behavior of some people in the society would induce sense of rejection in them. Participant 6 in this regard stated that: "Our most difficult period was the first year of each grade; the children did not allow me sit beside them or they would change their sit (because of me)."

4.1.2.1.4. Excessive Support and Pity

Excessive worry, sympathy, and pitiful treatment by others and in turn inessential supports not only failed to help these people but also caused resentment among them and induction of a role of disability. The interpretation of PWA about pity and sympathy was receiving help and sympathy without necessity or request by the person. Participant 8 stated that: "My teachers did my homework themselves (without my request); I got a bad feeling because I felt I am disabled and saw I have no solution."

4.1.2.2. Challenges Associated with Emotional Relationships and Marriage

Regarding establishment of emotional relationships and marriage, these people seldom received positive feedbacks because of clear apparent differences with people not suffering from albinism as well as the prejudiced and biased-laden treatments in the society. These negative feedbacks caused PWA to have serious concerns about the possibility of a desirable marriage, and in case of experiencing numerous emotional failures, they may sometimes become disappointed. In this regard, participant 10 stated that: "What saddens me is mainly related to my family; I mean my parents may go somewhere and others say their girls haven't still got married, their girl has a problem, no one wants her (for marriage)."

4.1.2.3. Constraints in Selection and Persistence of Job

Since typically finding a desired job has serious difficulties, this difficulty is doubled for PWA due to eyesight constraints as well as the society's prejudices about this population such as belief in their disability and eccentricity. PWA due to the constraints they have in selection and

persistence of jobs sometimes experienced considerable financial and economic problems, complicating their conditions. Participant 8 stated that: "My main concern is job. I see my constraint (vision) prevents me from obtaining my favorite job." In spite of these mentioned challenges, these individuals have support sources helping them in coping with the challenges, which are mentioned further.

4.2. Perceived Sources of Support

The perceived sources of support include two sub-themes of social supports and access to facilitator tools.

4.2.1. Social Supports

Social supports had a key role in mitigating the stresses and challenges of PWA. Indeed, social support was the most important source for PWA in acquiring productive adaptation, which has been categorized into three subclasses.

4.2.1.1. Siblings with Albinism

Having siblings with albinism caused the person to feel they are not weird or isolated, and somehow facilitated the disease acceptance process. In addition, since siblings experience similar conditions to the PWA themselves, they could understand each other better and be a source of support for each other. In this regard, participant 11 stated that: "My siblings had also albinism; when I was born, they were already there. This itself caused the situation to seem somehow normal. There was no surprise or pity in our family and we were comfortable with each other, meaning that we were ourselves and had no external stress."

4.2.1.2. Supportive Family

For PWA, the family was the most important social unit, with many psychosocial functions. When the family could fulfill their duties regarding PWA, it would also respond to the essential needs including development of a sense of competence and autonomy. In this regard, participant 6 stated that: "My mother told me you have no special problem, and this positive spirit my parents gave me would enhance us and help us progress further."

4.2.1.3. Supportive Friends and Teachers

Some teachers and friends during the school days and even thereafter played a key supportive role for PWA. The type of relationship and feedback of friends and teachers had a lasting effect on their minds. Understanding the visual constraints and albinism-associated problems as well as relevant supports caused mitigation of anxieties as well as albinism-associated challenges. In this regard, participant 11 stated that: "For example, my math teacher read

anything he wrote on the blackboard aloud, since he knew I could not use the blackboard, and this understanding of my teacher gave me a good feeling.”

4.2.2. Access to Facilitator Tools

The vision-associated limitations have a close relationship with many anxieties, worries, and failures among PWA. Access to facilitator tools can considerably contribute to reducing the eyesight limitations. Equipment and tools such as eyeglasses, cellphone, music player/recorder, and electronic teaching aids are tools used by some PWA for mitigating the constraints. Participant 12 stated that: “My problems in my lessons had diminished to some extent, since I worked with teaching aids such as recorded audio files and large-font books as well as magnifier, whereby conditions improved for me.”

In addition to the sources of support helping these people in adaptation as well as mitigation of the albinism-associated problems, PWA had also psychological mechanisms, playing a key role in coping with the mentioned challenges.

4.3. The Psychological Mechanisms of Coping with Challenges

The psychological mechanisms of coping with challenges were categorized into adaptive and maladaptive, given the type of function they had.

4.3.1. Adaptive Psychological Mechanisms

Adaptive psychological mechanisms help the person accept and cope with the reality better, so that they would not distort the reality to a large extent, and then even enhance the social functioning and quality of life of the person. This category consists of five subcategories of forgiveness, anticipation/ preparation, attempt for success, relationship-seeking/empathy with peers, and being psychologically minded.

4.3.1.1. Forgiveness

Hatred and preoccupation about harming individuals, not only failed to enhance the mental health and peace of these people, but also contributed to aggravation of their psychological problems. Those who managed to forgive the harming individuals and did not experience severe hostility or hatred in relations with others, reported greater peace and calm. In this regard, participant 5 stated that: “My manager should have not expected me to be like others and should have not been this unfamiliar with the issue of albinism... anyway, I forgave his misdeeds and I have no bad feelings.”

4.3.1.2. Anticipation and Preparation

Having a sense of security is one of the most essential psychological needs of humans; humans use all of their senses and competences for providing security. In albinism, whereby one of the most essential senses of security provision, i.e., eyesight or vision, is impaired, for providing security and coping with challenges as well as acquiring adaptation, PWA sometimes used anticipation and preparation. Participant 13 stated that: “When I know my anxiety would be high, I have some solutions; for example, the day before the appointment, I go there, draw the croquis of the new place for finding the ways and rooms, and then memorize them.”

4.3.1.3. Attempt for Success

PWA who in spite of considerable limitations had the ability of flourishing their competences and achieving their goals would be more approved by the society and reported greater satisfaction with their conditions. In this regard, participant 2 stated that: “... Thanks to my teaching, I acquired three excellent ranks, causing others not to allow themselves express negative things... Success boosted my self-confidence and became a kind of support for heating no negative judgment by others.”

4.3.1.4. Relationship-seeking and Empathy with Peers

PWA who had accepted the disease constraints and problems, in addition to being interested in establishing communication with others who had no albinism, also showed willingness to communicate and have empathy with other PWA. Participant 1 stated that: “The Association of Albinism highly boosts my self-confidence. I’d love to help others especially other PWA. The guys in the association of albinism have the same problem as me, they feel disappointed, one should accept what cannot be changed.”

4.3.1.5. Psychological Mindedness

This refers to the person’s ability to see the relationships between thoughts, emotions, and actions, with the aim of learning meanings as well as causes of their experiences and behaviors (19). Psychologically minded PWA had greater competence in adaptive coping with the albinism-associated challenges. They had less impulsivity and had healthier confrontation with conflicts and stresses. In this regard, participant 11 stated that: “The behavior of any person is an outcome of a series of inner and previous issues in them. If an inappropriate behavior occurs by me, in fact I did that behavior, which has roots in the reaction of my mental forces, and is not your issue.”

4.3.2. Maladaptive Psychological Mechanisms

Some other psychological mechanisms, not only failed to help PWA in healthy confrontation with challenges, but also caused development of further problems and sometimes set the ground for development of psychological disorders. This class consists of five subcategories of projection, acting-out, self-attack, avoidance/helplessness, and lack of assertiveness.

4.3.2.1. Projection

Projection refers to attributing one's emotions and states to others; this psychological mechanism is the source of many psychological disorders and problems. Some PWA may unconsciously have an unpleasant image of themselves due to considerable traumatic experiences, and then attribute it to others, thereby experiencing anxiety, depression, and considerable sense of shame. Participant 11 stated that: "I blamed myself in any quarrel that had nothing to do with me. For example, when a dispute occurred between my parents, I told myself I am to blame; for example, they would wish to go out and felt embarrassed of having me."

4.3.2.2. Acting-out

Acting out refers to conversion of unpleasant emotions and conflicts to extreme behaviors such as aggression and scurrility. Some PWA, when facing challenges and stressors, instead of using adaptive mechanisms such as assertiveness, employed aggression and acting out. In this regard, participant 2 stated that: "One of the children showed curiosity about me and he wanted to tell others I read using a magnifier and ridiculed my hair color. Suddenly, I got angry, bet his head to the fence and broke his eyeglasses."

4.3.2.3. Self-attack

Some PWA who had experienced massive traumatic experiences during their developmental period coped with challenges through identification with the agent of harm and its internalization; they somehow showed a self-attack pattern and when confronting challenges; they showed behaviors such as assigning insulting and reprimanding terms to themselves or believed they are worthless. Participant 10 stated that: "If my eyesight functioned poorly, I told myself I am to blame, I am dumb (have low intelligence), I am lazy, and that is why I cannot see. I took such perceptions from my teachers, since they constantly admonished me."

4.3.2.4. Avoidance and Helplessness

One of the psychological mechanisms of PWA against conflicts and challenges was avoidance. Some PWA, when

they tried several times and failed constantly, felt a sense of helplessness and chose avoidance strategy. Possibly, due to experiencing these harms imposed in the social setting, PWA may use avoidance mechanism in order not to confront challenges such as ridicule, stigma, and curiosity by others. Meanwhile, due to physical constraints and community-based negative prejudices, these people are more at risk of failure and helplessness. In this regard, participant 13 stated that: "If I could not cope with the conditions, well I evade that issue such as studying; when I saw I could not handle my lessons due to weak eyesight, I dropped out of school and now before beginning any job, I think I would fail."

4.3.2.5. Lack of Assertiveness

Healthy individuals have the ability of experiencing anger and using it in a healthy way for assertiveness. In some PWA, the damages associated with self-esteem and projections as well as excessive worry about being harmed by close relationships caused the subject to experience problems and inferiorities regarding assertiveness along with healthy expression of self. Participant 7 in this regard stated that: "I could not see the classroom blackboard, and it was difficult for me, I needed to read the text to learn it. If I could not read, I absolutely could not learn. It was as if I did not want and could not share this problem with the teacher. I thought if I said, he would definitely despise me; I could never say it and it was a very bad feeling."

5. Discussion

The aim of present study was to examine the lived experience of people with albinism in Iran, whereby three main themes of challenges, perceived sources of support, and psychological mechanisms of coping with challenges were extracted, which are discussed in three parts.

5.1. Challenges

As previous studies (8, 20), reported eyesight and dermal challenges in PWA in line with these studies, body-based challenges including vision impairment and problems related to the skin were among the major challenges of PWA. Prior to this study, psychosocial challenges including discrimination, prejudice, and stigma have been the pivot of many qualitative studies about albinism (10, 20-22). The population of this research also experienced various psychosocial challenges in their daily lives, which are related to resenting by others. These individuals have been exposed to numerous experiences of prejudice, improper curiosity, ridicule, sense of pity as well as sense of rejection by community-oriented communications. It is important

to pay attention to the fact that violence and physical and mental abuse towards these people in other countries, especially African countries (23-25), were more intense and prevalent than in Iran, and people with albinism in Iran generally perceived the family as a source of support. Probably, the strong role of the family institution in Iran and the lack of superstitions and myths related to these people compared to African countries justifies the issue.

In social communications, some individuals due to unawareness and negative prejudices and even sometimes with the intention of assistance cause PWA resentment. The concept of resentment from social reaction of others in this research have been in line with previous studies (8, 11, 22, 26), which were associated with staring at PWA, immature questions, along with the public's unawareness about the albinism as well as experience of facing prejudice. However, these studies did not much deal with the concepts of excessive support and pity as unique experiences of PWA, which may be caused by the predominance of protective traits in Iranian culture. Further, due to the mentioned constraints and reasons, these individuals experience serious challenges in various areas of life including occupation and marriage.

Vision problems and negative prejudices in the society cause serious limitations for finding and persisting in jobs among PWA. Again, in previous studies (8, 11, 22, 26), occupational and academic constraints of PWA have been identified, which are in line with the present study results. Gaigher et al. in a study mentioned the challenges and problems of PWA in marriage, which concurs with the present study findings (27). The problems and challenges associated with albinism cause PWA sometimes experience problems in finding a marital partner and marriage such as serious constraints for selection and numerous failures, and thus they may have fear and frustration about the possibility of favorable marriage. During the analysis Iranian people with albinism data, we observed differences in the type of challenges associated with marriage and emotional relationships among both female and male participants. The female subjects had mostly fear, worry, and disappointment about the possibility of desirable marriage, but the major experience of male individuals was about failures in initiating emotional relationships. Since in Iranian culture, girls' social and romantic relationships are more limited compared to boys, and also the expression and requests to start a relationship mainly happen from boys, and women are less active in the field of emotional relationships, the combination of these factors with their physical limitations, creates more anxiety and fear about being chosen for marriage in women with albinism. But because expressing and asking for marriage is more common in boys, then, for this reason, they experience more

failures in emotional relationships and marriage.

5.2. Perceived Sources of Support

Social support which includes supports by friends/teachers, family, and siblings of PWA plays a key role in mitigating the anxiety and occupational pressures such as stigma and ridicule, which also improves their self-esteem. In this regard, previous studies (8, 10, 14, 28) have also mentioned the role of sources of social support such as family and friends in PWA, which is in line with the present study results.

In some African countries, stigma, superstitions, and stereotypes (10, 13, 20, 22) around albinism were more and more severe. The difference between the appearance of the affected person and the non-affected population was significant (14). Also, in general, there was little correct and necessary information for African families about PWA (29, 30), probably the pressure and interaction of these factors made the family of people with African albinism sometimes unable to play a solid supporting role. In contrast, in most Iranian families, the family played the most important supporting role in these people. Availability of healthy social relationships in addition to fulfilling the communication needs, by providing the possibility of receiving empathy and understanding that these individuals are not alone in experiencing many challenges, had a supportive role for PWA. The basis of the effectiveness of psychosocial support can be sought in self-determination theory of Deci and Ryan as well as the need to communicate, which reports relationship seeking as one of the essential needs among humans (31). Since many physical problems of PWA are not fully curable, in the study by Shah et al. (32), the positive role of this factor as well as facilitator equipment in PWA has been mentioned. Access to facilitator tools such as glasses and camera as well as other tools associated with improving academic and occupational performance can positively contribute to self-efficacy and in turn positive emotions among PWA.

5.3. Psychological Mechanisms of Coping with Challenges

In coping with challenges, PWA employs various psychological mechanisms, which are considered either adaptive or maladaptive regarding the function and proportion they have with conditions and reality. The adaptive mechanisms include forgiveness, anticipation/preparation, attempts for success, seeking relationships/sympathy with peers as well as psychological mindedness. These constitute a set of patterns through which the person can establish a relatively healthy and socially approvable relationship with reality. Aborisade (8) dealt with examining some coping strategies such as avoidance which are used

in PWA. However, they have not been successful in sufficiently addressing other psychological mechanisms of coping with challenges in these individuals. The findings of the present research have provided a new insight into psychological mechanisms of coping with challenges used by PWA, which are discussed further. In studies, Roberts et al. showed an inverse correlation between expression of anger and empathy (33). Also, Rey and Extremera found a positive relationship between the variables of forgiveness and quality of life (5). Thus, chronic animosity and hatred as well as lack of forgiving capacity (through blocking the capacity of empathy and affection) provide the ground for reducing quality of life. The findings of the present research proposed forgiveness as an adaptive psychological mechanism in coping with challenges.

Visual constraints impose massive challenges and anxiety for PWA. One of the adaptive mechanisms for coping with these challenges is anticipation and preparation, whereby the person anticipates these challenges before their occurrence and prepare themselves as well as the environment for safer confrontation. Past studies had not mentioned the mechanisms of anticipation and preparation among PWA, while the findings of the present research reported anticipation and preparation as a relatively common psychological mechanism among PWA. According to the findings of this research, some PWA attempt to achieve success in a serious and concentrated way for coping with challenges. Indeed, when PWA experience numerous failures because of physical and social constraints, they may make great attempts for achieving their goals and accomplishing important successes. Previous studies (34, 35) have shown correlation between the variables of success and self-efficacy as well as self-esteem. Meanwhile, this concept can be interpreted through Adler's inferiority complex theory (36), meaning that those who have physical disability or defects may attempt more using an active mechanism to cope with the sense of incompetence, weakness, and failure, and through the acquired successes they could have greater sense of self-efficacy, autonomy, and eventually greater sense of value.

Human relationships are the source and path of fulfilling human needs; if these relationships are healthy enough, they can prevent development of serious psychological damages (37). In a study showed a significant relationship between empathy and satisfaction with life. Some PWA in addition to being relationship seekers were also interested in empathy with other PWA. The capacity of empathy requires acceptance of reality and some degree of psychological health. Thus, when these individuals showed a positive tendency to active and empathetic communication with other PWA, they reported greater sense of peace.

The capacity of self-reflection and self-examination

can cause development of awareness and understanding about psychological patterns of the person. This awareness and understanding are an efficient tool for healthy coping with challenges of life. The individuals who were psychologically minded showed the ability of identifying and assessing their psychologically damaging patterns, and in turn this competence would facilitate correction and redefinition of maladaptive patterns. The basis of the effectiveness of this concept is possibly related to mentalization theory, i.e., the ability of understanding the psychological and emotional states of oneself and others (38).

Not all PWA used adaptive psychological mechanisms. The PWA who experience serious psychological issues employed maladaptive psychological mechanisms including projection, acting out, avoidance/helplessness, lack of assertiveness, and self-attack. These mechanisms not only failed to increase their quality of life, but also aggravated their problems and challenges. As Gabbard (39) has emphasized the role of projection in psychological disorders. Projection is both an immature defense mechanism and a cognitive distortion, through which the person seriously distorts the existing reality, and attributes the existence and responsibility of the unacceptable states inside their psyche to others. In some PWA, again projection showed a key role in dissatisfaction with life.

Some PWA who could not manage their anger when coping with challenges and had aggressive as well as impulsive behaviors, showed serious problems in social adaptation. Sometimes they even faced disciplinary and legal issues. The concept of containment refers to a capacity whereby, instead of applying impulsive behaviors and acting out, the person experiences the emotions related to realities and individuals in a healthy way (40) and cope with them in a more adaptive way. Possibly, according to the concept of containment, those who cannot tolerate their psychological conflicts, use more of acting out and aggressive behaviors when facing challenges.

Another maladaptive mechanism among PWA was avoiding challenging situations. The findings of this research in line with other studies (8, 41) showed the patterns of avoidance and detachment in PWA. When the possibility of adaptive and healthy confrontation with challenges diminishes, and the person experiences high insecurity and anxiety, and the cognitive and emotional capacity of the person are not in proportion with these challenges, the person may choose avoidance and detachment strategy in line with their personality structure. All these very albinism-associated failures and the mentioned avoidances subject the person to a sense of helplessness.

In line with the research by Marcon and Maia (6) who showed lack of assertiveness and problems of healthy expression in PWA, this research also indicated problems

of assertiveness in PWA. Lack of assertiveness predisposes PWA to underestimation and abuse by others, as well as under-flourishing of competencies and abilities. This lack of assertiveness is possibly due to damage of sense of value and self-esteem resulting from maladaptive mechanisms and other challenges.

As reported by Altman (7) most PWA suffer from lack of self-esteem; since in some of these individuals, the repeated experience of negative expressions and feedbacks by parents and others would damage their sense of self value, these individuals may sometimes identify themselves with such expressions and images, and somehow internalize these expressions and feedbacks. Later, they would treat themselves as the damaging agents treated them. This problem may create a psychological pattern or mechanism whereby the person would cope with their challenges through self-attack, thereby adversely affecting the quality of life by these maladaptive mechanisms.

5.4. Strengths and Limitations

This research, which is one of the few types of research that have investigated the psychosocial experiences of people with albinism in Iran, for the first time coherently way, extracted the adaptive and maladaptive defense mechanisms of these people in dealing with challenges and tensions. This research had some limitations to declare. Sampling of this research was available sampling and most participants were those who were at relatively high levels of occupation and academia compared to more general PWA. Unfortunately, most individuals coping with more serious challenges and problems or those with unsuitable conditions academically and occupationally did not show any willingness to participate in the research, and it is suggested to also include the experiences of this group as well.

5.5. Conclusions

The aim of the present research was to identify the lived experiences of PWA. The research findings indicated that Iranian PWA are coping with various physical and psychosocial challenges, which complicated their conditions. There were perceived sources of stress against these challenges, which would be harnessed by these individuals in necessary occasions. In addition, not all PWA would show the same psychological reaction to these challenges, and they would use adaptive or maladaptive psychological mechanisms in line with the personality structure they have. Eventually, this would create considerable differences in adaptation and quality of life of these people. The findings of this research can be employed in creating and planning the curricula as well as educational and healthcare programs of rehabilitation counseling along with other psychosocial interventions.

Footnotes

Authors' Contribution: T. A.: Conducting interviews, conceptualization, methodology, formal analysis, writing the original draft; B. B.: Conceptualization, methodology, formal analysis, supervision, writing the review and editing; M. S. K.: Conceptualization, methodology, formal analysis, supervision, writing, review and editing; M. A.: Conceptualization, formal analysis, writing, review and editing; S. S.: Conceptualization, methodology, formal analysis; M. V.: Methodology, validation, formal analysis.

Conflict of Interests: The researchers declare that there are no conflicts of interests in this research.

Data Reproducibility: The data presented in this study are uploaded during submission as a supplementary file and are openly available for readers upon request.

Ethical Approval: Ethical approval for the current study was obtained from committee of the University of Social Welfare and Rehabilitation Sciences (IR.USWR.REC.1399.017).

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