

Experience of patients with neurofibromatosis: A qualitative research

Samira Foji¹, Eesa Mohammadi², Akram Sanagoo¹, Leila Jouybari³

¹PhD, Student in Nursing, School of Nursing and Midwifery, Golestan University of Medical Sciences, Gorgan, Iran,

³Nursing Research Center, Golestan University of Medical Sciences, Gorgan, ²Department of Nursing, Faculty of Medical Sciences, Tarbiat Modares University, Tehran, Iran

ORCID:

Samira Foji: <https://orcid.org/0000-0001-5157-1848>;

Leila Jouybari: <https://orcid.org/0000-0003-2113-318X>

Abstract

Context: Neurofibromatosis type 1 (NF1) is one of the most common genetic skin disorders that impose significant psychological and social pressure on patients.

Aim: The objective of the study was to explore the experiences of patients with neurofibromatosis.

Setting and Design: Iran - qualitative study

Materials and Methods: This qualitative study was conducted in 2020. Eighteen patients with Neurofibromatosis type 1 (NF1) entered the study with maximum variation through purposeful sampling. Semi-structured interviews were used to collect data.

Statistical Analysis Used: Conventional content analysis method was used for the data analysis.

Results: Based on analyzed data, five categories including “Feeling defective and incompetent,” “Succumbing”, “Perceived social deprivation”, “Encountering oppression and violation of rights”, and “Rejection” were found.

Conclusion: It was shown that patients with NF1 had unpleasant experiences. Besides the challenges that they had to tolerate with the nature and symptoms of the disease, the disease imposed severe social and psychological pressures on them. Based on findings, it is essential to establish supportive strategies that would help patients deal with problems of the disease effectively.

Keywords: Content analysis, Neurofibromatosis 1, Nursing, Qualitative study

Address for correspondence: Dr. Leila Jouybari, Nursing Research Center, Golestan University of Medical Sciences, Gorgan, Iran.

E-mail: jouybari@gmail.com

Received: 15 September 2020; **Accepted:** 13 January 2021; **Published:** 19 July 2021

INTRODUCTION

Neurofibromatosis type 1 (NF1) is one of the most common genetic skin disorders with a significant

psychological and social burden on the patient.^[1] Its diagnosis is based on clinical evaluation. The common symptoms include café au lait spots, neurofibromas on the skin, plexiform neurofibromas, Lisch’s hamartomas,

Access this article online	
Quick Response Code:	Website: www.jnmsjournal.org
	DOI: 10.4103/jnms.jnms_126_20

This is an open access journal, and articles are distributed under the terms of the Creative Commons Attribution-NonCommercial-ShareAlike 4.0 License, which allows others to remix, tweak, and build upon the work non-commercially, as long as appropriate credit is given and the new creations are licensed under the identical terms.

For reprints contact: WKHLRPMedknow_reprints@wolterskluwer.com

How to cite this article: Foji S, Mohammadi E, Sanagoo A, Jouybari L. Experience of patients with neurofibromatosis: A qualitative research. *J Nurs Midwifery Sci* 2021;8:163-70.

optic pathway glioma, axillary freckling, and bone dysplasia. These patients are also susceptible to benign and malignant tumors.^[2] Emerging in childhood and with a wide phenotypic variation NF1 is inherited and autosomal dominant in 50% of cases. It affects approximately one out of every 3000 births.^[3] One of the challenging aspects of - NF1 is its unpredictable nature, various severe symptoms, and clinical complications. In addition, as the patients' appearances change and some may receive negative reactions, this disorder can cause the, patients with NF1 suffer from many social, behavioral, and emotional problems such as anxiety, depression, and low self-esteem, they have a misconception about their body, isolate themselves and avoid society, have difficulty in forming interpersonal relationships, have problems with interactions, have weaker social skills, and have difficulty in managing issues that relate to their appearance.^[4] Most studies carried out on the concerned subject have been quantitative^[5,6] and/or focused on children and adolescents.^[3,4] Since few studies have focused on the emotional and psychological effects of NF1,^[7,8] qualitative design suitable for investigating individuals' experiences of NF1.^[9] A look at these studies shows that this is the first quantitative study conducted in Iran on the quality of life of NF1 patients. Moreover, other qualitative studies and concept analysis have been abroad.^[10-12] Hence, the aim of the present study is to explore patients' perception of NF1 on their lives. This study is the first to investigate NF1 patients' experiences with the disease.

MATERIALS AND METHODS

Design

This study was based on a naturalistic research paradigm^[13,14] with, in which a conventional content analysis method is used. Given the purpose of the present study, this systematic method was used to provide an in-depth description of the concerned issue. This model is suitable for investigating individuals' experiences with any particular issue.^[15] In addition, the model is especially promising when there is less known about a given issue and there have been few studies devoted to it.^[16]

Participants

Purposeful sampling was used to select participants with rich experiences and then the snowball sampling method was used to seek other participants.^[13,14] The participants were male and female NF1 patients from four provinces in (Golestan, Mazandaran, Tehran, and Khorasan) in Iran. First participants were introduced by the NF1 Association. The inclusion criteria were being over 18 years of age, being diagnosed with the disease

Table 1: Demographic characteristics of the participants

Variable	n
Gender	
Male	8
Female	10
Age	
20-30	5
30-40	7
>40	6
Marital status	
Married	5
Single	12
Divorced	1
Job	
Employee	3
Housewife	8
Self-employed	3
Jobless	4
Equation	
Elementary	5
Diploma	8
Bachelor of science	1
Master	4

and approved by the NF1 Association, being aware of their diagnosis, being treated for the disorder, having the disorder for at least 6 months, and willing to participate in the study. Participants were introduced by the NF1 Association. Sampling continued until data saturation was reached where no new codes could be found from interviewing participants. The purpose was to select a variety of participants from both sexes, with different marital and educational status, from different age groups, and with different occupations [Table 1].

Data collection

In order to collect the data, unstructured interviews were conducted from September 2019 to March 2020. For the interview, first, a list of some leading questions was prepared based on the purpose of study. Every interview began with a general question such as "Please describe a regular day of having neurofibromatosis?" and then based on the answer, the interview continued with questions like: "How has your family received you and your condition?", "How has the society received you?" After answering the question, based on the purpose and the method of the study, probing questions such as "How?" and "Can you explain more and tell me an experience in this regard?" were asked for events related to the phenomenon. Eighteen face-to-face interviews were held in locations chosen by participants, which were mainly places where they felt comfortable such as their home, workplace, and the park. Interviews took between 90 and 190 min or on average 90 min. All interviews were recorded and typed word by word, along with the participants' nonverbal behavior (movements, facial expressions, etc.) in Microsoft Word software.

Ethical considerations

The Ethics Committee of Golestan University of Medical Sciences approved this study under the following Code of Ethics (IR.GOUMS.REC.1398.231). Informed consent was obtained from all participants regarding their participation in the research by clarifying for them the purpose, nature and method of study. The place, time, and duration of the interview were selected based on the participant's preference. Participants were assured of the confidentiality of their information and audio files. They were informed of their rights of withdrawing from the study in anytime without question and keeping the data confidentiality by not revealing the name of the participant.

Data analysis

Data analysis was done by the use of conventional content analysis method. After the interviews were typed, all materials were placed in MAXQDA software version 10 to better organize data. For immersing in the data, the interviews were read several times. According to Zhang and Wildemuth's (2009), the qualitative content analysis process follows eight stages: define the unit of analysis, develop categories and a coding scheme, test your coding scheme on a sample of text, code all the text, assess your coding consistency, draw conclusions from the coded data, and report your methods and findings. To this end, a text was developed based on the research questions, from which semantic units were extracted, and a code was assigned to each. After taking the interviews, primary codes were extracted, categorized, and labeled based on their conceptual similarity. Through this, the subcategories were defined and after applying necessary modifications, they were grouped into more abstract general main categories. The main categories were also grouped into more abstract concepts called themes.^[15,17]

Rigor

To ensure the rigor of findings, Lincoln and Guba's 4 criteria were used.^[14,15] To ensure the credibility of findings, all extracted codes from interviews were checked with the five NF1 patients and necessary modifications were made. All interviews were reviewed, approved, and confirmed by the other authors. To ensure the dependability of findings, the process of research and all its stages were recorded and reported step by step as accurately as possible. Furthermore, the attempt was to have various participants in age, sex, education, marital status, place of residence, and severity of disease to ensure maximum variation, which besides ensuring acceptability, also contributed to the transferability of findings.

RESULTS

The participants were eight male patients and ten female patients with NF1, age range of 20–50 years, single and married, divorced, employed and unemployed, and primary education to master's degree. Based on data analysis, one main category with five categories were proposed: “feeling defective and incompetent,” “succumbing,” “perceived social deprivation,” “encountering oppression and violation of rights,” and “rejection.” In addition, 19 subcategories were considered [Table 2] which reflected NF1 patients' perception of the disease. Describing and interpreting the results using direct participant quotes are provided below.

Feeling defective and incompetent

This expresses emotions such as “feeling unsatisfied with appearance,” “being different from others,” “being preoccupied with the disorder,” “feeling tormented by the disorder,” “losing self-esteem,” and “fearing disorder progression.” “Feeling unsatisfied with one's appearance” is the first trait of “feeling defective and incompetent.” Patients' mental image of their bodies may change as nodules and freckles become more obvious.

“... From 16, I would go in front of the mirror and wonder why my eyes were like that and I would get so mad about the way I looked” P5 (female, 21 years).

Another participant expressed her unhappiness and change as:

“I feel so ugly” (P12, Female, 27 years).

“Being different from others” is the next trait of “feeling defective and incompetent.” This may make individuals unwilling to appear in the society.

Table 2: Main category, category and subcategories extracted from content analysis

Category	Subcategory
Feeling defective and incompetent	Feeling unsatisfied with appearance
	Being different from others
	Being preoccupied with the disorder
	Feeling tormented by the disorder
	Losing self-esteem
Succumbing	Fearing disorder progression
	Concealing the disorder
	Distancing one from others
Perceive social deprivation	Disease intolerance
	Deprived of marriage
	Limitation in wearing clothes
	Employment failure
	Educational problems
Encountering oppression and violation of rights Rejection	Deprived from governmental support
	Mocked and belittled by others
	Being offended by the curiosity of others
	Encountering other's sarcastic behavior
	Limitation in connections and presence in society Loneliness and being abandoned

“I would ask things like How come my sisters aren’t like me? Why are they different? Am I not their sister or are they not my mother’s children? Why did I have to become like this?... I kept thinking that I wasn’t their child and if I really was how come I looked like this” (P11, female, 33 years).

Another trait of “feeling defective and incompetence” is “being preoccupied with the illness.” As NF1 is recurrent and unpredictable in nature, patients may encounter a variety of challenges and difficulties that are likely to preoccupy them.

“I have this disorder, and since my freckles keep increasing, I constantly fear that it might get to my eyes. I am always thinking about the disease at home and event at work” (P15, male, 27 years).

“Feeling tormented by the disorder” is another trait in this category. When nodules appear on the face as a sign of the progression of the disorder, it may cause patients to feel tormented by the disorder. A married woman who had been suffering from the illness for over 20 years said:

“Sometimes I say what the hell are you! I get up in the morning and I see a few more have been added and I get upset, and I tell myself how I mock myself about how fortunate I am. It’s like you constantly want to be covered up-” (P13, female 48 years).

“Losing self-esteem” is the next trait here. Humiliation, ridicule, educational problems, and learning difficulties are among the various factors that negatively affect patients’ self-esteem.

“We’re walking down the street and a girl comes by who is selling flowers and we said we didn’t want any. The girl then told my friend ‘Mam, you’re much prettier, you by one.’ It’s these things that really reduce your self-esteem. I was going to break into tears back then” (P12, female, 27 years).

Finally, the last trait is “fearing disorder progression.” Due to the progressive nature of the disease and the appearance of symptoms over time, and due to the limitations, it causes in social attendance and relations, patients fear the progression of their disease:

“These worsen by the minute and when they get worse it grows more and then my connection with the society will be cut off, and this makes me anxious and depressed” (P18, male, 50 years).

Succumbing

This concept represents the patient’s unwillingness to stay strong and resist disease; to rephrase, the patient not only does not confront but also tries to conceal it to prevent its continuation and severity. These patients do not wish to share information about the real state of their disease. In addition, patients distance themselves from the inappropriate behavior of others. Based on the gathered data, the following issues reflect on how patients have succumbed, this concept in clouding: “concealing the disorder,” “distancing one from others,” and “disease intolerance.”

The first subcategory of “succumbing” here is “concealing the disorder.” Patients try to conceal their disease because they fear insight of other and try to prevent possible ridicule, social isolation, and discrimination. Also to avoid further curiosity and advice of others, they try to conceal the disease by giving limited and even unrealistic information just to get out of the situation. A participant shared how she tried to avoid being mocked by concealing her disease:

“I kept withdrawing myself and constantly thought about how they didn’t have anything on their necks, not even a spot. I didn’t have a nodule back then, I was just a little withdrawn at the time. I just kept thinking that if someone would see it they’d mock me” (P13, female, 48 years).

Another participant’s experience:

“Everywhere we go people ask ‘what are those on your face (or neck or hand)?’ And I’d lie about it, they’d ask ‘what happened to you?’ And I’d say my skin had burned or was showing an allergic reaction to some food I’d eaten earlier” (P10, female, 37 years).

“Distancing one from others” is the next trait of “succumbing” here. Patients distance themselves and limit their commute to avoid irritating situations and the inappropriate behavior of others.

“If I ever wanted to go swimming, people’s attention would be drawn to me and they’d start asking questions. This is why I try to avoid public places so I’d be asked fewer questions” (P6, male, 35 years).

“Disease intolerance” is in the last subcategory. Due to their disorder, NF1 patients deal with difficult conditions and are concerned about its progression. The stress caused by this can impede these patients from tolerating the disease, where in worse cases may even lead to suicide:

“... I can't bear it anymore. I can't stand this disease and I'm always thinking about suicide. When I die it'll all be over” (P7, female, 26 years).

Perceiving social deprivation

NF1 patients' social life is affected by the changes in their appearance which somewhat deprives them from their social rights and privileges.

The first subcategory here is “Deprived of marriage.” One of the challenges that these patients encounter is getting married and pregnant. NF1 is highly transmittable from parents to children as it is a gene-transmitted disorder, which makes childbearing a challenging issue for these patients. Furthermore, the appearance of nodules and freckles on patient's skin and the worsening of their condition, their deformities, and the recurrent internal nodules of patients have turned marriage into a challenging issue for these patients.

A participant stated that she was deprived of marriage because of her illness:

“...Anyway, people are looking for a pretty woman (to get married to) and it's obvious that a person with my condition isn't appealing to anyone” (P15, female, 42 years).

Most participants find marriage impossible because of their condition:

“I can't ever get married even if I wanted to marry someone like myself, it's hard to find someone. And still if I did, there would be no way on Earth that we could have kids. No one in their right mind would ever marry us and this bugs me” (P11, female, 33 years).

“Limitation in wearing clothes” is another trait of “perceived social deprivation.” The marks on visible parts of the body will raise curiosity, trigger questions, cause fear, and distance people from these patients. Therefore, patients try to select clothes that would cover most parts of their body. One of the participants who was a student living in a dormitory shared her experience as follows:

“The first time I wore shorts in the dormitory, they started asking about the freckles that I had here and there, and there was this one time when my skin looked as if it was peeled. And everyone was afraid to sit beside me so I started wearing long-sleeves all the time even when I went to weddings” (P3, female, 35 years).

Another subcategory is employment failure. Facial changes, due to the disorder, affect the patient's beauty and appearance

making it difficult for them to find a job. In addition, occasionally, the public society may fear that the disorder is contagious, which adds to the problems even more.

“There were a couple of places that I attended which told me that they were looking for someone good looking and handsome to attract more customers – not to scare them away.” (P11, female, 33 years).

“(I used to go to) a kindergarten (manager) said, ma'am... you being here and your face looking like that scares the moms and makes them not wanting to bring their children here anymore. I attended two or three other places and they refused me.” (P3, female, 35 years).

Next subcategory is educational problems. Patients with NF1 experience some degree of learning disorder due to the nature of their illness, which in turn has caused patients to encounter academic and mental difficulties.

“It really affected my studies and I just stopped studying and doing my assignments. I kept thinking about my disease” (P7, male, 27 years).

The last trait of perceived social deprivation is being deprived of governmental support. Patients all acknowledged that they did not have governmental support services such as medical insurance and support from organizations such as disability benefits, and in general, no special support was provided for them.

“I went to the Welfare center, and the Head of the center didn't care much about me and my condition. I asked where to go and from whom to seek support, and I even wrote a letter to the president but there was never a reply. I didn't care but I went to the Welfare center and told them that I had this disease and asked for a loan but they didn't care either” (P7, male, 27 years).

Encountering oppression and violation of rights

NF1 patients may encounter violent behavior, be humiliated and/or ridiculed because of their disease. On the other hand, because of the disorder, these patients are deprived of their rights in various situations and face discrimination. Patients expressed their experience with encountering oppression by such as like “being humiliated and ridiculed by others,” “being offended by the curiosity of others,” and “confronting the belittling behavior of others.”

The first subcategory here is mocked and belittled by others. This theme expresses a feeling of being

unappreciated and devalued which reduces the patient's self-esteem. Patients feel they are being treated in a light-hearted ridiculous manner, humiliated, and addressed with inappropriate titles.

“My cousin is aware that I have this disorder, he keeps his distance when I'm talking to him like he thinks it's contagious, he once said look at his body AGHH it's like a Dalmatian's” (P7, male, 27 years).

Another trait is being offended by the curiosity of others. Patients feel that those around them are trying to find out about their personal life, disease and conditions by curiously asking questions. However, patients and families want to keep these issues to themselves and are reluctant to provide information about the illness. This discomfort was shared by many participants:

“Ordinary people, like when I go swimming I have this really big freckle here on my leg, and just anyone feels they can ask what the freckle is or how it has gotten there or whether I was burned or something” (P12, female, 26 years).

Encountering others' sarcastic behavior is another subcategory. Patients had encountered people who treated them sarcastically like giving inappropriate suggestions about removing the skin nodules or comparing the patient with others, or having boisterous behavior.

“I have a cousin who has really good skin and she kept showing off like if I would ever put on some cream she'd say *how much cream are you going to wear? What do you expect to cover?* or like she'd just say to my face *your skin is so terrible and mine is great*” (P12, female, 26 years).

Another participant with severe skeletal and facial impairments described his experience of being ridiculed as follows:

“For example, in the park, people tell their children that if you don't listen you'll end-up like this guy, or children point at me and tell each other to look, so I don't go out much in the society” (P18, male, 50 years).

Rejection

This concept reflects on how these patients feel about people's distancing and avoidance when they encounter them. Rejection comes with a feeling of loneliness when people refuse to communicate with a person.

The first trait is “Limitation in connections and presence in society.” Patients are often confronted with questions and curiosities about their nodules and freckles, and when

they compare themselves to others, patients prefer to avoid the public because they feel self-conscious.

“The fact that I can't go to the places I enjoy, like swimming, get-togethers, parties (she breaks into tears). I can't go to any of them. Even when my friends get together I don't go” (P13, female, 48 years).

Another trait here is. “Loneliness and being abandoned.” NF1 patients' appearances, nodules, and freckles have caused others to abandon them as they fear to become infected; therefore, patients experience loneliness.

“... I had a boyfriend, a boy who was my friend just to stop feeling lonely because the other girls would not be friends with me so I became friends with a boy but then he said you are too ugly and useless so he left me as well and this was added (to my problems)” (P3, female, 35 years).

“They don't like me, they don't want to shake hands even if I were to offer it to greet them warmly, they'd frown and pull back, those who are prestigious and polite, however, would make an excuse like a cold or something and would apologize for not shaking hands because they were afraid that I might catch something!., so childish” (P17, male, 24 years).

DISCUSSION

The findings of this study showed that NF1 patients express their experiences in the following forms: “feeling defective and incompetent,” “succumbing,” “perceiving social deprivation,” “encountering oppression and violation of rights,” and “rejection. These experiences represent psychological and social suffering. In other words, although these experiences are caused by a physical injury, nodules, and skin lesions, their suffering and effects are purely psychosocial. The complexity of these emotions indicates a traumatic psychological and social experience. The results of the present study were similar with Rezayat, *et al.* (2019). Dalgard *et al.* studied the mental burden of skin disease and showed that social problems may intensify negative emotions, maladaptive thinking processes (having a defect), undesirable self-perception (loss of self-esteem and negative body image), and negative behavioral patterns (oversocial avoidance). As a result, psychosocial complications such as depression, suicidal motivation, and anxiety were common among skin patients.^[18]

In addition, Aghaei *et al.*'s, showed that patients with acne were dissatisfied with their body image. They had a lack of attractiveness and in turn experienced low quality of life.^[19]

The study done by Granström *et al.* on the mental pressure and stress imposed by NF1 on adult patients also revealed that the adult patients with NF1 have a more negative and adverse perception of their body compared to other patients suffering from other complications.^[12]

Other concepts in this study were succumbing to the condition, and being intolerant toward the disease in such way that patients could no longer endure the problems of their disorder, which lead some patients to attempt to suicide. Picardi *et al.* also found that patients with psoriasis are unable to adapt effectively to the disease and experience intolerance because they feel embarrassed by their body and have had negative experiences in their social interactions.^[20]

As an important factor in encountering stressful life events, social support can alleviate psychological distress and has positive effects on the mental health of patients. Due to the manifestations of the disorder (nodules and freckles), NF1 patients often face the curiosity and interrogations of others. They are limited in selecting their outfits and clothes because of their condition and as they want to conceal their lesions. On the other hand, the specific condition and complications of the disease have limited made patients' lives in terms of marriage, employment, and education.

Davern and O'Donnell showed that acne in patients with this disorder leads to limitations in wearing clothes for daily activities in such a way that patients attempt to cover the lesions from others in order to prevent inappropriate reactions. Patients had difficulty participating in sports and social activities, and some were even unable to play or participate because of their skin condition. In terms of work and school, it was found that some patients experienced problems at work and school because they were unable to concentrate sufficiently and had difficulty performing their duties. Some also claimed that they had problems with sex because they felt embarrassed and undervalued due to the lesions.^[21]

In this study, patients experienced ridicule, humiliation, and sarcasm as their privacy was violated.

Young focused on the psychosocial stress caused by psoriasis and found that experiencing humiliation can leave a profound effect on a patient's self-esteem which may develop negative assumptions in the patient's mind.^[22]

Patients' experiences in the present study indicated that NF1 patients were deprived of social opportunities because of the humiliation that they received and the failure they experienced at work. Warren *et al.*'s also reported that the

psoriasis patients experienced humiliation, and rejection, which left a negative impact on their job performance.^[23]

Patients suffering from rare disorders and complications are faced with challenges which go beyond medical ones. Many of these challenges can be controlled through increasing the public awareness about these rare disorders and through concentrating on mental health and compatibility strategies.

Limitations

The patients invited to study were those who were members of the NF1 Association. Perhaps those who were not members and were not identified had different experiences that were beyond the control of researchers.

CONCLUSION

This study showed that NF1 patients have endured painful experiences despite the fact that their disorder is physical. They have experienced emotional and psychosocial affliction. These experiences can impose more psychological burden in addition to the stress caused by the nature of the disease and its symptoms. Researchers and specialists need to design appropriate methods or mechanisms to help patients deal with disease. Then, they need to provide a ground work to implement the designed mechanisms, thereby reducing the risks of problem in patients with NF1. Since problems for NF1 patients are result of cognitive distortions of the society and individuals themselves, this problem can be solved through positive interaction between individuals and society. Community-based interventions between NF1 patients and the society an soon enough lead to positive interactions. It seems that interventions and the programs of governmental and nongovernmental organizations regarding rare diseases can make psychosocial adjustment of NF1 patients more possible.

Conflicts of interest

There are no conflicts of interest.

Authors' contribution

All of the authors had complete contribution in designing, data analysis, writing and revising manuscript, critical reviewing and approval of final draft. S.F, A.S, L.J participated in data collection.

Financial support and sponsorship

Nil.

Acknowledgements

This study is part of the PhD dissertation of first author and also approved research project at the deputy of

research and technology of Golestan University of Medical Sciences. The authors sincerely thank the board of the Iranian Neurofibromatosis Supportive Association and all the neurofibromatosis patients who shared their valuable experiences in this study.

REFERENCES

- Armand ML, Taieb C, Bourgeois A, Bourlier M, Bennani M, Bodemer C, *et al.* Burden of adult neurofibromatosis 1: Development and validation of a burden assessment tool. *Orphanet J Rare Dis* 2019;14:94.
- Baudou E, Nemmi F, Biotteau M, Maziero S, Peran P, Chaix Y. Can the cognitive phenotype in neurofibromatosis type 1 (NF1) be explained by neuroimaging? A review. *Front Neurol* 2019;10:1373.
- Barke J, Coad J, Harcourt D. Parents' experiences of caring for a young person with neurofibromatosis type 1 (NF1): A qualitative study. *J Commun Gen* 2016;7:33-9.
- Klein-Tasman BP, Colon AM, Brei N, van der Fluit F, Casnar CL, Janke KM, *et al.* Adaptive behavior in young children with neurofibromatosis type 1. *Int J Pediatr* 2013;2013:690432.
- Sanagoo A, Jouybari L, Koochi F, Sayehmiri F. Evaluation of QoL in neurofibromatosis patients: A systematic review and meta-analysis study. *BMC Neurol* 2019;19:123.
- Page PZ, Page GP, Ecosse E, Korf BR, Leplege A, Wolkenstein P. Impact of neurofibromatosis 1 on quality of life: A cross-sectional study of 176 American cases. *Am J Med Gen Part A* 2006;140:1893-8.
- Rosnau K, Hashmi SS, Northrup H, Slopis J, Noblin S, Ashfaq M. Knowledge and Self-esteem of individuals with neurofibromatosis type 1 (NF1). *J Genet Couns* 2017;26:620-7.
- Wang DL, Smith KB, Esparza S, Leigh FA, Muzikansky A, Park ER, *et al.* Emotional functioning of patients with neurofibromatosis tumor suppressor syndrome. *Genet Med* 2012;14:977-82.
- Crawford HA, Barton B, Wilson MJ, Berman Y, McKelvey-Martin VJ, Morrison PJ, *et al.* The impact of neurofibromatosis type 1 on the health and wellbeing of Australian adults. *J Genet Couns* 2015;24:931-44.
- Soghi I, Saeedi S, Sanagoo A, Jouybari L, Ebrahimirad M, Mehravar F. Quality of life in a group of Iranian patients with neurofibromatosis type 1 with cutaneous expressions. *J Mazandaran Univ Med Sci* 2018;28:95-103.
- Rezapoor Esfahani M, Joybari L, Sanagoo A, Araghian Mojarad F. Experiences of living with neurofibromatosis in a young woman: A case report. *Shafay Khatam* 2017;5:264-5.
- Granström S, Langenbruch A, Augustin M, Mautner VF. Psychological burden in adult neurofibromatosis type 1 patients: Impact of disease visibility on body image. *Dermatology* 2012;224:160-7.
- PolitDF. *Essentials of Nursing Research*. Philadelphia, Wolters Kluwer Health/Lippincott Williams & Wilkins; 2010.
- Speziale HS, Streubert HJ, Carpenter DR. *Qualitative Research in Nursing: Advancing the Humanistic Imperative*. PolitDF. *Essentials of Nursing Research*. Philadelphia, Wolters Kluwer Health/Lippincott Williams & Wilkins; 2010.
- Elo S, Kyngäs H. The qualitative content analysis process. *J Adv Nurs* 2008;62:107-15.
- Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res* 2005;15:1277-88.
- Zhang Y, Wildemuth BM. Qualitative analysis of content. *Appl Soc Res Methods Questions Inform Lib Sci* 2009;308:319.
- Dalgard FJ, Gieler U, Tomas-Aragones L, Lien L, Poot F, Jemec GB, *et al.* The psychological burden of skin diseases: A cross-sectional multicenter study among dermatological out-patients in 13 European countries. *J Invest Dermatol* 2015;135:984-91.
- Aghaei S, Mazharinia N, Jafari P, Abbasfard Z. The Persian version of the Cardiff acne disability index. Reliability and validity study. *Saudi Med J* 2006;27:80-2.
- Picardi A, Mazzotti E, Gaetano P, Cattaruzza MS, Baliva G, Melchi CF, *et al.* Stress, social support, emotional regulation, and exacerbation of diffuse plaque psoriasis. *Psychosomatics* 2005;46:556-64.
- Davern J, O'Donnell AT. Stigma predicts health-related quality of life impairment, psychological distress, and somatic symptoms in acne sufferers. *PLoS One* 2018;13:e0205009.
- Young M. The psychological and social burdens of psoriasis. *Dermatol Nurs* 2005;17:15-9.
- Warren R, Kleyn C, Gulliver W. Cumulative life course impairment in psoriasis: Patient perception of disease-related impairment throughout the life course. *Br J Dermatol* 2011;164:1-4.