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Review

Problems of psychological assistance to patients with neurofibromatosis type I

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Abstract: Neurofibromatosis type I is one of the most common hereditary tumor syndromes and is characterized by the development of multiple skin and subcutaneous tumors on the body, disfiguring the appearance of patients. The literature search strategy on psychological care for patients with neurofibromatosis type I included searching for relevant articles in Scopus, Web of Science, and PubMed. Half of patients with neurofibromatosis type I develop plexiform neurofibromas, which can compress internal organs, deform the face or limbs, and impair self-care and social adaptation. Surgical methods are used to treat cutaneous and subcutaneous neurofibromas, but the number of these tumors is increasing, causing serious psychological trauma to patients. In this regard, common problems of patients with neurofibromatosis type I, in addition to tumor damage, are psychological disorders such as anxiety, depression, and distress. These disorders worsen the quality of life of patients and require qualified psychological assistance. This article examines the nature and frequency of psychological disorders in patients with neurofibromatosis type I, as well as problems associated with the availability of psychological assistance. Measures are proposed for the timely identification of distress, anxiety and depression in patients and their treatment with routing for consultations with the necessary specialists. An analysis of the scientific literature shows a lack of publications in the field of research into the psychological problems of patients with neurofibromatosis type I compared to cancer patients. Future directions of research in this area should involve active involvement of department staff, psychotherapists and psychologists in the examination of patients with neurofibromatosis type I throughout the world.

Keywords: quality of life; neurofibromatosis type I; tumors; psychological assistance; psychological disorders

1. Introduction

Neurofibromatosis type 1 (NF1) is one of the most common hereditary tumor syndromes with an autosomal dominant type of inheritance. NF1 is caused by heterozygous mutations in the tumor suppressor gene NF1. The incidence of NF1 in the world is 1:3164 of the population [1]. About half of NF1 cases are sporadic due to newly occurring mutations in the parents' germ cells (80% in sperm) [2]. Characteristic manifestations of the disease are cutaneous and/or subcutaneous neurofibromas in more than 99% of patients with NF1 [3], multiple pigmented spots on the skin in 96.5%, and freckling of the axillary and groin areas in 90% of patients with NF1 [4]. Hamartomas of the iris are found in 70% of patients, plexiform neurofibromas—in half of patients with NF1 [3]. The incidence of optic nerve gliomas in this disease is 27%, brain tumors—10%, hydrocephalus—7.7% [5]. Malignant peripheral nerve sheath tumors (MPNSTs) are extremely rare and aggressive neoplasms in the general population, but account for 13% of cases in patients with NF1. These tumors typically arise from pre-existing plexiform

neurofibromas [6]. The appearance of multiple tumors on the body worsens the quality of life of patients, as it causes severe psychological discomfort and vulnerability to the crippling consequences of NF1. The number of tumors increases every year, which affects the deterioration of the psychological state of patients. Particularly significant are the effects of plexiform neurofibromas, which disfigure the appearance of patients when they are localized on the face or cause pain syndrome when growing along the nerve roots of the spinal cord [3].

In addition to the tumor syndrome, cognitive impairment in patients with NF1 is diffuse and noticeable throughout life [2]. According to the conducted meta-analyses, seizure syndrome is determined in 8.1% of patients with NF1 (of which generalized tonic-clonic seizures in 16.8%, focal seizures in 54.2%; against the background of 1–2 anticonvulsant drugs, the absence of seizures is determined in 68.5%; median age is 3.5–12 years) [7]. Intellectual disabilities leading to learning difficulties are determined in 40% of NF1 cases, the average IQ is 85–90. Autism spectrum disorders are determined in 25%–30% of patients with NF1, attention deficit hyperactivity disorder—40% [2]. Patients with NF1 are characterized by damage to the musculoskeletal system. According to a meta-analysis, approximately 26.6% of patients with NF1 have scoliosis, in most cases severe. As a rule, it develops in early childhood, most often affecting the thoracic spine [8]. On average, 5% of NF1 patients worldwide have pseudoarthrosis [3], and 24% have short stature [9].

Quality of life in patients with NF1 is impaired due to cosmetic defects, serious complications and uncertainty regarding prognosis and disease progression [10]. Low quality of life associated with cosmetic skin defects is associated with low levels of self-confidence and self-esteem, as well as high levels of anxiety and depressive symptoms [11]. Cognitive impairment in NF1 can also negatively impact psychological well-being [12]. In addition to mental disorders caused by the stress of changing appearance of patients due to multiple disfiguring tumors on the body, patients with NF1 suffer from psychological disorders due to brain pathology due to the disease itself. Patients with NF1 are characterized by an increased incidence of autism spectrum disorders, attention deficit hyperactivity disorder, severe stress response disorder, and unipolar depression. The cumulative incidence of first hospital admission for any mental disorder by age 30 was 28% for men and 35% for women with NF1 [13]. Compared with healthy peers, children with NF1 are characterized by difficulties in interaction, poorer social skills, and internalizing and externalizing behavior problems [14]. Autism spectrum disorders are found in 30%–60% of patients with NF1, attention deficit hyperactivity disorder—in 25%–30% of patients with NF1 [2].

Adults with NF1 develop a negative body image, which is expressed in a significantly lower sense of attractiveness and self-confidence, physical anxiety, and sexual dissatisfaction with their body [15]. Plexiform neurofibromas have a particularly pronounced impact on psychological well-being in patients with NF1. Children with these tumors show significantly worse results than population norms in 8 of 10 domains (including anxiety, depressive symptoms, positive affect, psychosocial stress, fatigue, meaning and purpose, peer relationships, and pain interference) [16]. A comprehensive study of patients with NF1 shows a variety of

psychological disorders and needs not only in medical but also in mental and socioeconomic areas at different ages [17]. Almost all children and adults with NF1 are characterized by a low quality of life, especially in psychological terms [18]. Thus, complex damage to various organs and tissues in NF1 contributes to the development of psychological disorders in patients, which worsen their quality of life (**Figure 1**). This has a negative impact on the psychological well-being of patients, preventing them from realizing their abilities as individuals. Psychological well-being is a holistic experience that reflects the success of an individual's functioning in a social environment [19]. For the treatment of plexiform neurofibromas in patients with NF1, a mitogen-activated protein kinase inhibitor is currently used, which allows for a reduction in the size of tumors, but does not cure patients completely, despite constant use of the drug [20,21]. Surgical excision and laser are used to remove multiple skin tumors in patients with NF1. Unfortunately, this treatment method is not included in clinical recommendations, and doctors often underestimate the need for early removal of neurofibromas. When the entire body of patients with NF1 is covered with multiple tumors, it is not possible to excise the entire surface of the skin [22]. The shortcomings of existing studies of neurofibromatosis type 1 include the emphasis on determining the genetic causes of the disease, the description of many mutations in the NF1 gene [23–26], characteristics of the distribution [1] and clinical manifestations of NF1 [2–8], while such studies do not describe the characteristics of psychological disorders in patients and methods of their treatment. In this regard, it is relevant to consider the frequency of occurrence of psychological disorders in patients with NF1, their types and effective methods of their treatment.

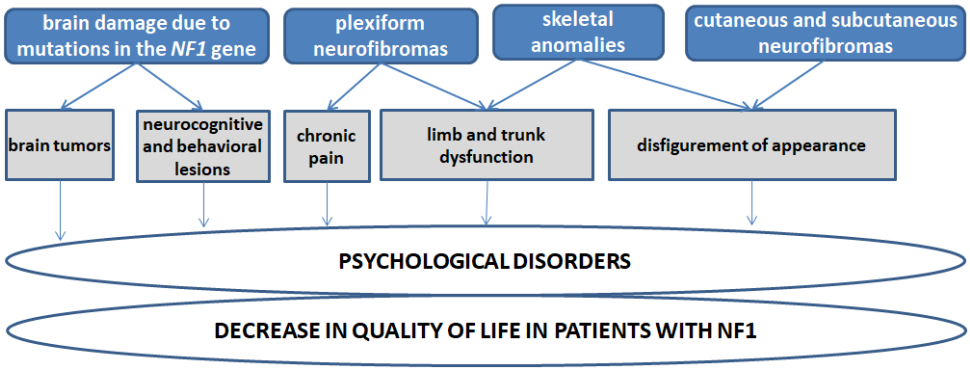

Figure 1. The influence of various factors of neurofibromatosis type 1 on the development of psychological disorders in affected individuals.

2. Literature search strategy

The literature search strategy on psychological care for patients with neurofibromatosis type 1 included searching for relevant articles in the Scopus, Web of Science, and PubMed databases using the phrases "neurofibromatosis type 1" with words "depression," "anxiety," "stress," "psychological care", "psychotherapy". The literature search was conducted in the time range from 2003 to 2025, with an emphasis on examining scientific articles over the past 5 years. The inclusion criteria were original articles with statistically reliable data. Exclusion criteria included

review articles and scientific publications with unreliable and unconfirmed data. Data extraction from articles was performed by proofreading the articles. Analysis of the obtained data showed the presence of 79 articles describing depression in patients with NF1, 67 articles describing anxiety in them, 108 articles describing stress in them, 32 articles describing psychological assistance in patients with NF1. At the same time, psychological problems of cancer patients are given much more attention, since there are 26,931 articles describing depression in cancer patients, 20,728 describing anxiety in them, 39,275 articles describing stress in them, 18,146 articles describing psychological assistance in them.

3. Psychological disorders in patients with neurofibromatosis type I

Patients with NF1 are characterized by an increased level of stress caused by the development of multiple progressive tumors on their body with the lack of modern effective methods for their radical treatment. As a result, the quality of life of patients with NF1 turned out to be significantly lower than not only the general population, but also patients with other hereditary tumor syndromes, such as neurofibromatosis type 2 [27]. Patients with NF1 have been shown to have higher levels of perceived stress and lower levels of self-esteem compared to the general population [28]. Psychological stress in patients with NF1 was entirely mediated by how patients perceived their bodies disfigured by multiple tumors [15]. Higher stress levels have been found in NF1 patients with a high number of neurofibromas on the skin, as this increases the level of self-doubt [11]. Because multiple neurofibromas develop in 99% of affected individuals, with progressive increases in size and number with age [3], patients with NF1 in childhood and adulthood are characterized by long-term distress [18]. The psychosocial profiles of adaptation to NF1 were characterized by indicators of psychosocial functioning (perceived stress, depression, anxiety) and resilience (optimism, empathy, awareness, social support, coping). As a result, 57% of patients with NF1 were classified as “low adaptation” with high emotional distress and low resilience [29]. A structural analysis of basic quality of life indicators, including psychological health, emotional distress (depression, anxiety) and resilience in adult patients with NF1 was conducted. As a result, a negative relationship was determined between emotional distress and quality of life [30].

Patients with NF1 were found to have higher levels of depression and anxiety associated with more frequent self-reported medical visits in the past year [28]. Depression found to be partly mediated by tumor-induced pain intensity in NF1 patients [31]. Clinical depression is found in 55% of adult patients with NF1 (61% of women and 43% of men). In a multivariate regression model, depressive symptoms accounted for 32% of the variance in the quality of life index [32]. In a nationwide study of adults with NF1 in Denmark, 19% had symptoms of depression and 15% had symptoms of anxiety [33]. A study of patients with NF1 in Canada found anxiety/depression in 60% of patients [34]. A nationwide study in Japan found anxiety/depression in 45% of patients with NF1, with the severity of dermatological symptoms being significantly associated with moderate to severe subjective and mental health-related quality of life components, with a tendency to worsen in

younger patients and females [35]. According to data from patients with NF1 in Australia, clinical anxiety was identified in 23% of them [36]. In UK patients with NF1 and plexiform neurofibromas, anxiety and depression were found in 51.4% of cases [37].

Depression in cancer patients associated with demoralization and increased risk of suicide [38]. Study of NF1 patients in France shows 4-fold increased risk of suicide compared to general population [39]. Studies in Italy have shown that suicidal thoughts are detected in patients with NF1 significantly more often (45%) than in the general population and control groups [40]. In the United States, suicidal ideation was found in 19% of adults with NF1 and was associated with depression and poor psychological quality of life [41]. It should be noted that psychological disorders are characteristic not only of patients with NF1 themselves, but also of their family members. Mothers of children with NF1 have been found to have significantly higher stress levels compared to mothers of typically developing children [42]. Comprehensive study of families of patients confirms high levels of stress in parents of patients with NF1 [17]. It was noted that parents of children with NF1 exhibit more symptoms of psychological disorders (anxiety, depression) compared to their affected children [43].

Since the quality of life of patients with NF1 is significantly reduced compared to the general population and even compared to patients with other hereditary tumor syndromes, it is necessary to introduce consultations with psychologists and psychiatrists into clinical guidelines for such patients. Such measures could promptly identify existing psychological disorders in patients with NF1 and provide psychological assistance to improve their quality of life. Since a higher level of stress is determined in patients with a large number of neurofibromas on their skin, a measure to eliminate stress could be surgical removal of these tumors. Since one of the causes of depression in patients with NF1 may be pain caused by tumors, doctors need to prescribe painkillers in a timely manner and, if possible, refer patients for surgical treatment of tumors that cause pain. It is also important to prescribe targeted therapy with a mitogen-activated protein kinase inhibitor for the treatment of plexiform neurofibromas, the development of which in patients with NF1 is significantly associated with depression. Psychological assistance to patients and their relatives should be included in the comprehensive treatment of patients with NF1, which would significantly alleviate their psychological state, prolong life and prevent suicide attempts.

4. Psychological assistance to patients with neurofibromatosis type I

Psychological disorders developing in patients with NF1 and deterioration of quality of life hinder social adaptation of patients with NF1 and their successful employment. This, in turn, further reduces quality of life, contributing to the progression of anxiety and depression. Therefore, timely and high-quality psychological assistance to patients with NF1 is an important factor in the realization of patients as individuals [44]. A survey of adults with NF1 showed that they need professional support to address psychological and work-related problems. The highest level of need is associated with a more severe course of the disease [33].

How NF1 patients cope with their physical disabilities associated with multiple tumors on their bodies significantly affects their psychosocial adjustment and emotional functioning [11]. Therefore, timely provision of qualified psychological assistance is an important factor in the treatment of patients with NF1, especially in the absence of other treatment methods (contraindications to surgical excision of neurofibromas, relapses, inoperable tumors, malignancy). However, monitoring of social problems associated with NF1 is often not part of standardized care for patients with NF1 [17]. Currently, there is no psychosocial screening tool developed for rapid assessment of symptoms of decreased quality of life in patients with NF1 [14].

A systematic review of the scientific literature conducted in 2024 showed that there is no standardized neuropsychological assessment for adults with NF1. It is proposed to create a specific neuropsychological battery to determine cognitive and psychological impairments in patients [12]. The psychosocial difficulties experienced by patients with NF1 and their family members should be taken into account at the healthcare level in order to formally implement effective psychological rehabilitation programs [45]. But to assess the quality of life of patients with NF1, special questionnaires such as BoN (Burden of Neurofibromatosis) can be used [10]. Assessment of psychological disorders can be carried out using a distress thermometer (DT) [14]. To assess the need for psychological assistance, the following questionnaires may be offered: Coping Orientation to Problem Experiences (COPE), Skindex-29, Padua Skin-Related QoL questionnaire (PSRQ), State-Trait Anxiety Inventory-X2 form (STAI-X2), Depression Questionnaire (DQ) and Rosenberg Self-Esteem Scale (RSES) [11]. Questionnaires of life satisfaction, posttraumatic growth, and mindfulness are used [46]. One of the validated measures of psychological and social well-being is the Patient-Reported Outcomes Measurement Information System (PROMIS). The use of this system allows comparison of the indicators of patients with NF1 and the general population [47].

Organizing psychological assistance to patients with NF1 and their families is a complex, intricate process that involves psychologists, psychiatrists, treating physicians, people around the patients, as well as various ways of organizing this process (**Figure 2**). One of the most accessible methods is the organization of online support groups. Thanks to this, it is possible to conduct free psychological help sessions at a time convenient for patients without distraction from household chores and without the need for prior appointments [48]. Such groups are also important for identifying suicidal patients and providing them with timely psychological support to prevent possible suicide [40]. Using virtual mind-body groups for adolescents with NF1 resulted in improvements in several resilience factors for overcoming NF1-related difficulties [49]. Patients with NF1 received an 8-week group intervention based on mind-body skills, the resilience relaxation response program, aimed at increasing resilience and life satisfaction. Further testing showed significant improvements in resilience, life satisfaction, depression, stress, anxiety, mindfulness, and post-traumatic growth, with effect sizes ranging from 0.73 to 1.33 [46]. An 8-week mind-body program to enhance resilience through relaxation response in NF1 resulted in stable increases in several dimensions of resilience (mindfulness,

perceived social support, perceived coping abilities) [50]. Another study also found positive results (improved mindfulness, coping, and gratitude) from 8 weeks of using a website-based mind-body intervention (NF-Web) for adults with NF1 [51].

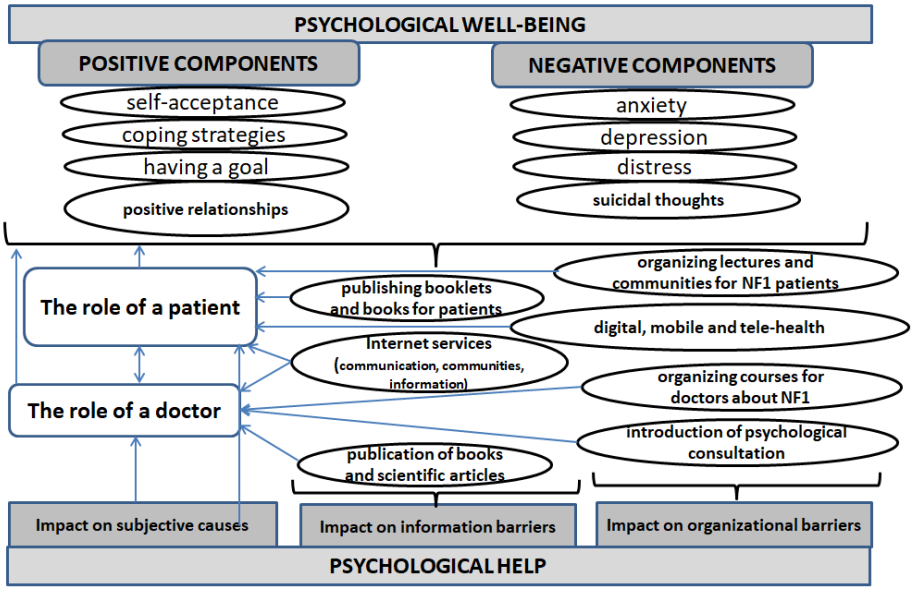

Figure 2. Scheme of proposed methods of influencing psychological well-being in patients with NF1.

Acceptance and commitment therapy (ACT) helps people refocus on valued relationships and activities (especially in NF1 patients with chronic pain due to plexiform neurofibromas) and has also been shown to be effective in improving quality of life in NF1 [52]. Psychosocial interventions in NF1 have been shown to be effective in improving patients' quality of life [20]. Because dysfunctional beliefs about one's own abilities play an important role in the distress that comes with developing a high number of skin tumors in patients with NF1, psychological counseling and coping skills treatment aimed at improving perceived self-efficacy and developing more adaptive coping strategies may be effective methods [11]. To alleviate the mental suffering of patients with NF1, attention and support from the state and sponsoring organizations is required [18]. A comparatively effective method of psychotherapy in improving the mental health of patients with NF1 is the method of individual training in dialectical behavioral therapy skills. Thanks to this approach, patients with NF1 develop their skills with improved psychological well-being [53]. In addition to usual care, a brief self-management intervention consisting of 6 weeks of self-help books and telephone peer counseling has shown comparative effectiveness in the psychotherapy of patients with NF1 [54]. The relative effectiveness of an 8-week group mind body skills based intervention, the relaxation response resiliency program (3RP) aimed at improving resiliency and increasing satisfaction with life, has also been shown in patients with NF1 [46]. An analysis of scientific literature has shown a limitation of studies on the effectiveness of psychotherapy for patients with NF1, compared to that for patients with malignant neoplasms. This may be due to the rarer occurrence of NF1 compared to sporadic malignant neoplasms in the population, as well as less emphasis on the psychological

problems of such patients. Therefore, it can be assumed that patients with NF1 will use similar methods of psychotherapy and organization of psychological assistance that are used for cancer patients.

It can be assumed that the same principles as for patients with malignant neoplasms can be applied to the organization of psychological assistance for patients with NF1, since half of patients with NF1 develop plexiform neurofibromas, the complete cure of which is still impossible despite the surgical methods and targeted therapy. Patient education schools, information booklets, patient diaries and effective communication with healthcare professionals are relevant [55]. A promising application of mindfulness-based stress reduction techniques has been shown to be effective in treating anxiety and depressive symptoms in cancer patients [56]. Since disfigurement by multiple neurofibromas plays an important role in the development of psychological disorders in patients with NF1, therapy is needed to improve self-acceptance, which can include group art therapy with drawing [57] and psychological relaxation [58]. Self-assessment scales are used to determine self-acceptance in patients with NF1 when prescribing these treatment methods and for dynamic monitoring of their effectiveness (Self-Image Scale—SIS) [59].

Patients with NF1 and their family members need proper genetic counseling by competent geneticists who are aware of effective psychological techniques in communication with cancer patients. Optimal would also be consultations together with psychologists who could identify during the conversation the psychological problems of the counselors. During genetic counseling, comprehensive knowledge about the disease regarding clinical and genetic aspects can be offered, in addition to psychological support. Preventive strategies, psychological and bioethical issues can be discussed. It is well known that stress and anxiety “due to the unknown” are usually reduced by scientific knowledge provided in a psychologically supportive environment during genetic counseling. This can lead to better prevention, clinical, psychological and genetic, as well as to a better prognosis. Since there are effective surgical methods for the treatment of multiple neurofibromas, this information should be voiced during genetic counseling. Geneticists around the world prescribe mitogen-activated protein kinase inhibitors to treat plexiform neurofibromas. Sharing this information can help alleviate the patient’s fear of diagnostic imaging (such as whole-body MRI) to detect hidden tumors early and begin treatment. Genetic counseling can also discuss possible prevention of new cases through prenatal or preimplantation testing. Such measures will allow NF1 patients to feel like full-fledged members of society, worthy of creating families and healthy children. In addition, preimplantation diagnostics, if actively implemented in the practice of geneticists in different countries, will further reduce the number of NF1 patients in the world.

An analysis of scientific literature has shown that the organization of psychological assistance to patients with NF1, despite its relevance, is not included in the standards of their treatment. Therefore, in modern society, it is necessary to actualize the problems of NF1 in healthcare, among the population and in the media. It is important to train doctors in psychological techniques when communicating with patients with NF1 for the timely detection of psychological disorders and referral to specialized specialists, such as psychologists and psychiatrists. Also, the

introduction of universal questionnaires and questionnaires described in this chapter into the standards of care of patients with NF1 by geneticists and oncologists is promising, based on the results of filling out which it is possible to determine the psychological problems of patients. The creation of online and offline communication groups for NF1 patients, united by common problems, would improve their quality of life. The organization of conferences dedicated to the psychological problems of NF1 patients could also identify promising paths of action in this direction both in individual countries and worldwide.

5. Additional methods that improve psychological well-being in patients with type I neurofibromatosis

Since an important factor in the development of psychological disorders in patients with NF1 is a cosmetic defect due to multiple disfiguring neurofibromas [15], as well as the development of progressive plexiform neurofibromas [16], surgery to get rid of tumors can be a factor in improving the psychological state. Indeed, surgical resection of neurofibromas has been shown to improve quality of life in patients with NF1 with moderate complications [60]. Electrocoagulation of cutaneous neurofibromas is also a highly effective method [61]. Since anxiety, depression and stress levels increase with a higher number of neurofibromas on the skin, an effective strategy against such psychological disorders is timely excision of tumors. Moreover, with significant spread of them, surgical treatment becomes difficult [11]. The method of choice is a surgical laser, which complies with the principles of ablastics and antiblastics, allowing hundreds of skin tumors to be removed in one session without subsequent scarring or relapse [62–64]. Modern therapy with the mitogen-activated protein kinase inhibitor selumetinib will slow the growth of plexiform neurofibromas and even reduce their size, which gives patients with NF1 and their relatives hope for a better prognosis and the possibility of full functioning. According to meta-analyses, the improvement rate for inoperable plexiform neurofibromas with selumetinib is 75.3% for pain and 77.8% for movement disorders [21].

Despite the availability of effective treatments for NF1 manifestations, such as electrocoagulation [61] and laser [62–64], the use of selumetinib [21], there are a number of limitations in the provision of such care, which primarily rest on funding. Indeed, selumetinib is an expensive drug and is prescribed by special organizations to children under 18 years of age with inoperable plexiform neurofibromas [21]. There is evidence of the effectiveness of topical application of this drug [65], but this method is not included in the list of medical and economic standards and is not covered by insurance companies. Given the difficulties in finding employment for patients with NF1 [44], purchasing such an expensive drug that could at least partially relieve them of cosmetic defects is unaffordable for them. In addition, it was noted that even electrocoagulation of cutaneous neurofibromas is also not included in the list of medical and economic standards. And it is necessary that insurance companies provide coverage for the removal of tumors in patients with NF1 [61]. Since skeletal abnormalities are also factors limiting the functionality and work capacity of patients with NF1, correction of these defects is necessary. In the

treatment of scoliosis in patients with NF1, spondylodesis and growing rod technique have shown the best results in terms of efficiency and safety [8]. It is necessary to excise cutaneous neurofibromas as early as possible, since the disseminated process can occupy all of the skin, and then it will be impossible to remove tumors that occupy the entire surface of the skin (**Figure 3**). There are other obstacles to timely correction of cosmetic defects, which include psychological disorders of patients. Indeed, the presence of multiple skin and subcutaneous tumors causes despair in patients who no longer believe in a cure and do not go to see a doctor who could prescribe therapy or surgical excision. In this regard, it is important to organize free psychological assistance to all patients with NF1 to prepare them for treatment of the disease. At the same time, psychologists and psychotherapists themselves should be informed about effective methods of healing in order to instill hope and confidence in a good prognosis. Obstacles to the correct treatment of NF1 are also the illiteracy of doctors, since there is a biased opinion that excision of neurofibromas can provoke the growth of new tumors. In fact, an analysis of the scientific literature suggests that surgical removal [60], especially with electrocoagulation [61] or laser [62–64], gives good results with minimal recurrence. To overcome this obstacle, it is necessary to inform doctors about this through articles in journals, presentations at medical conferences, and when teaching students at medical schools.

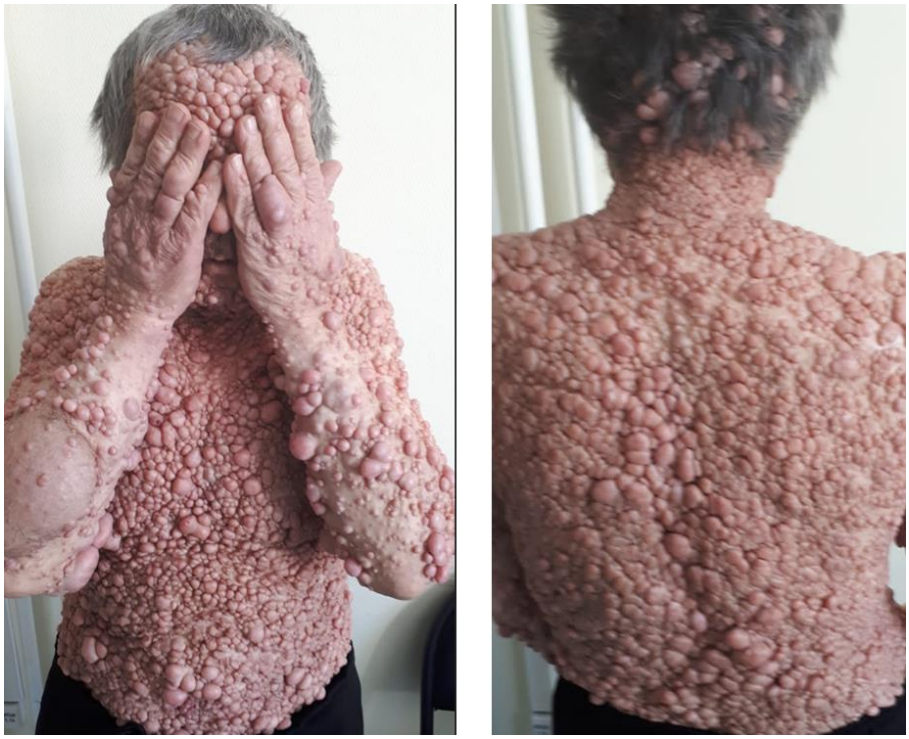

Figure 3. Photo of a patient with multiple neurofibromas occupying almost the entire surface of the skin (photo by the author, taken with the patient's permission using ethical standards and rules).

Thus, to improve the psychological well-being of patients with NF1, a comprehensive approach is needed involving specialists from various fields, including not only psychologists, psychiatrists and neurologists, but also surgeons, neurosurgeons and oncologists. An important component for preventing

psychological disorders and improving the quality of life of patients with NF1 is the adoption of measures for surgical excision of tumors of the skin, subcutaneous tissue and brain, the appointment of targeted therapy. These methods must use modern treatment methods and adherence to measures to prevent the spread of the tumor process. It is necessary to overcome social factors that prevent NF1 patients from freely receiving the necessary drugs for the treatment of the tumor syndrome. Geneticists, surgeons and even psychologists should be aware that timely excision of neurofibromas can eliminate cosmetic defects in NF1 patients and prevent tumor recurrence. Patients with NF1 should be full-fledged members of our society, worthy of a good profession, self-realization and quality of life. Future scientific research should be aimed at a comprehensive study of the molecular mechanisms of NF1, tumor manifestations and lesions of various organs and systems, as well as their impact on the psychological state of patients. In the future, it is possible to develop effective methods of psychological therapy for patients with NF1 to improve their psychological well-being. Coordination of the work of doctors and psychologists in this area is necessary, allowing for increasing the literacy of each specialist.

6. Conclusion

Neurofibromatosis type 1 is one of the most common and severe hereditary tumor syndromes, causing not only physical but also mental suffering in patients. To treat tumor syndrome in NF1, surgical methods of excision of neurofibromas, removal of tumors using an electrocoagulator and laser, as well as treatment of plexiform neurofibromas with mitogen-activated protein kinase inhibitors are used. In addition to the neurological disorders caused by the disease itself, most patients with NF1 develop poor adaptation with high emotional distress and low resilience. According to data from different countries, clinical depression develops in 19% to 55% of patients with NF1. Patients with NF1 are characterized by a significantly increased risk of suicide (4 times), and suicidal thoughts, according to data from various authors, are determined in 19%–45% of patients with NF1. Family members of NF1 patients are prone to increased levels of stress and the development of anxiety and depression. Therefore, it is important to organize timely and effective psychological assistance to NF1 patients and their relatives. This task is assigned not only to treating physicians, but also to healthcare organizations and insurance companies in different countries to ensure availability of free consultations with psychologists and psychotherapists to all NF1 patients in need of psychological assistance. It is necessary to develop and introduce effective methods of psychotherapy into the clinic. Additional resources designed to improve the quality of life of patients with NF1 include online communities that promote the development of positive components of psychological well-being. An important factor for this is also the hope for a better prognosis and getting rid of disfiguring tumors. It is therefore important that physicians are aware of the possibility of referring patients with NF1 to effective treatment, which would give hope to patients. It should also be noted that NF1 is a severe hereditary disease, reliably associated with psychological disorders due to primary disorders and secondarily due to disfigurement of the body by multiple tumors, for which psychological assistance

can be developed and assessed appropriately. Psychologists should be aware of such diseases and be able to provide effective assistance to patients with NF1, and develop new programs for the diagnosis and treatment of psychological disorders. A critical analysis of existing research has shown that little attention is currently paid to the psychological problems of patients with neurofibromatosis type 1 compared to cancer patients. There are almost 1000 times more articles in scientific databases devoted to psychological problems and psychological care for cancer patients than for NF1 patients. This demonstrates the need to highlight the existing problem in scientific circles, conduct more original work, and involve psychologists in the study of NF1 patients around the world.

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Informed consent statement: Not applicable.

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