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Patient Perceptions and Advocacy in Ichthyosis: A Review of Psychosocial and Supportive Care Models

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ABSTRACT

Background: Ichthyosis is a range of rare, genetically heterogeneous conditions that are skin disorders caused by over-scaling and hindrance in skin barrier. Clinical care has made a significant improvement however; patients experience very serious psychosocial, emotional and societal difficulties. **Objective:** The objective of this review is to highlight the perception and the quality of life of the patients affected by ichthyosis experience and the role of advocacy and sponsorship organizations in championing patient-centered care.
Method: A comprehensive literature search was conducted across databases including PubMed, Scopus, and Google Scholar for articles published up to May 2024. Studies focusing on patient experiences, advocacy efforts, and care strategies in ichthyosis were included. Quality assessment was performed using the Critical Appraisal Skills Program (CASP) for qualitative studies and the Newcastle-Ottawa Scale (NOS) for observational studies. **Results:** Thematic analysis revealed three findings: (1) high psychological and social load patients face because of visible symptoms, (2) emotional distress and social isolation, and (3) stratification points in communication between patients and healthcare providers. Advocacy organizations like the Foundation for

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Ichthyosis & Related Skin Types (FIRST) were identified as instrumental in education, psychosocial support, as well as policy advocacy.

Conclusion: Ichthyosis management should not only be limited to clinical outcomes but should also focus on emotional and social wellbeing of the patient. The networks of sponsorship and advocacy play a crucial role in closing the care gaps and enabling patients.

1 INTRODUCTION

Ichthyosis, a group of skin-related disorders that are distinguished by unusual thickening of the skin, has long been a complex issue for both healthcare professionals and patients (Butala *et al.*, 2023; Park *et al.*, 2023). The lifestyle of an individual affected by Ichthyosis is only slightly impacted by the visible symptoms, which include dry, coarse, and scaly skin (Table 1). The severity of Ichthyosis is manifold and across-the-board due to the inadequate treatment opportunities and social denouncement (Jovandaric & Milenkovic, 2021). Despite encroachments in medical care and research, a dire requirement for a holistic methodology that integrates advocacy determinations and patient viewpoints is perceived (Hemrajani *et al.*, 2022). The aim of this review is to conduct an in-depth study of the emotions faced by persons with Ichthyosis.

The significance of giving patient-centered attention is effectively managing this kind of situation and the function of advocacy groups in offering help. Ichthyosis is a group of more than 20 hereditary skin disorders, each of which is classified (Fischer *et al.*, 2023; Murashkin *et al.*, 2022; Park *et al.*, 2023). The effect of ichthyosis is severe, despite its rarity, with prevalence rates ranging from around 1 in 250 to 1 in 200,000 patients globally (Marukian & Choate, 2016). Due to the observable nature of the disorder persons suffering from Ichthyosis mostly have to experience psychological suffering and societal disgrace in addition to physical embarrassment (Fischer *et al.*, 2023). Moreover, the deficiency of particular attention and inadequate treatment possibilities intensify the trials tackled by patients, emphasizing the immediate requirement for a more inclusive and patient-based methodology to care as shown in **Table 1**.

2 MATERIALS AND METHODS

A precise literature search was carried out to collect related articles. Databanks, including Google Scholar, PubMed, and Scopus, were utilized to isolate research published until May 2024. "Sponsorship groups," "Ichthyosis," "patient-oriented care," "patient perceptions," "prevalence,’’ and "advocacy groups," were the keywords used in the research. To guarantee a complete comprehension of patient understandings and the role of advocacy in Ichthyosis supervision, both quantitative and qualitative studies were equally incorporated. Inclusive criteria comprise like articles discussing patient awareness and understanding of having Ichthyosis, studies concentrating on the role of support and sponsorship groups in Ichthyosis administration, research articles, reviews, and clinical trials discovering patient-centered care models for Ichthyosis, and publications providing data on the genetic factors, domination, and impact of various kinds of Ichthyosis. Whereas exclusive criteria were that those articles that were not in English were excluded, those studies that were not discussing patient advocacy or care studies focus merely on the pathophysiology or molecular biology of Ichthyosis were also excluded, less than 10 contributors were observed in case series and reports, opinion pieces, conference abstracts, and letters to the editor.

Table 1: Genetic Causes, Prevalence, and Associated Symptoms of Ichthyosis

Type of Ichthyosis	Genetic Cause	OMIM	Prevalence Rate	Physical Impact	Emotional Impact	Social Impact	References
Ichthyosis vulgaris	Autosomal dominant	146700	1 in 250	Itching, Scaling & Functional restrictions	Psychological suffering, Self-consciousness & Shame	Social segregation & Limited social interactions	Butala *et al*., 2023; Park *et al*., 2023; Hemrajani *et al*., 2022; Fischer *et al*., 2023; Marukian & Choate, 2016
Lamellar Ichthyosis	Autosomal recessive	242300	1 in 200,000	Itching, Scaling & Functional restrictions	Psychological suffering, Self-consciousness & Shame	Social segregation & Limited social interactions	Park *et al*., 2023; Fischer *et al*., 2023; Murashkin *et al*., 2022; Marukian & Choate, 2016
X-Linked Ichthyosis	X-linked recessive	308100	1 in 200,000	Itching, Scaling & Functional restrictions	Psychological suffering, Self-consciousness & Shame	Social segregation & Limited social interactions	Butala *et al*., 2023; Park *et al*., 2023; Hemrajani *et al*., 2022; Marukian & Choate, 2016
Harlequin Ichthyosis	Autosomal recessive	242500	1 in 1,000,000	Itching, Scaling & Functional restrictions	Psychological suffering, Self-consciousness & Shame	Social segregation & Limited social interactions	Butala *et al*., 2023; Park *et al*., 2023; Hemrajani *et al*., 2022; Marukian & Choate, 2016
Netherton Syndrome	Autosomal recessive	256500	1 in 200,000	Itching, Scaling & Functional restrictions	Psychological suffering, Self-consciousness & Shame	Social segregation & Limited social interactions	Park *et al*., 2023; Hemrajani *et al*., 2022; Fischer *et al*., 2023; Murashkin *et al*., 2022; Marukian & Choate, 2016

Study features (study design, authors, year of publication), genetic reasons, types of Ichthyoses, physical and emotional influences, dominance rates, and the part of advocacy groups were included in the extracted material. Information about patient-centered care simulations and patient up-keeping schemes was also acknowledged.

For qualitative studies, modified versions of the Critical Appraisal Skills Program (CASP) checklist were used to assess the excellence of the incorporated studies, and for observational studies the Newcastle-Ottawa Scale (NOS) was used. Evaluation of the precision of research inquiries, accuracy in data assortment, suitability of study projects, and rationality of results were included in this assessment. A descriptive synthesis approach was engaged to encapsulate and assimilate the results from the involved studies. Qualitative data was studied thematically to recognize key arrangements and understandings associated to patient insights, sponsorship, and patient-centered care in Ichthyosis whereas quantitative data was concise using descriptive statistics. The amalgamation is intended to offer a complete understanding of the trials tackled by patients with Ichthyosis and the role of advocacy clutches in addressing these trials.

3 KEY THEMES IN PATIENT PERCEPTIONS AND SPONSORSHIP

3.1 The Importance of Support and Patient's thinking

Considering the importance of support and patients thinking in modeling healthcare distribution is vital to discussing the trials of Ichthyosis. The existing understandings and determinations of patients regularly treated by primitive methods of care lead to a gap between healthcare workers and those they attend. Different opinions of patients and doctors on the severity and impact of Ichthyosis have been revealed by the research, which highlights the necessity for better association and consideration (Steinert *et al*., 2023; Walsh *et al*., 2023). Healthcare specialists can well associate treatment objectives with patient priorities by approving a patient-oriented methodology, thus increasing results and enriching the worth of life (Hannon *et al*., 2023).

3.2 The Existed Opinion of Patients

The existed opinion of persons having this condition offer valuable understanding of the multidimensional tasks caused by Ichthyosis. Patients have to fight with emotional grief, social separation, and the cruel burdens of treating their skin condition day-to-day in addition to the physical signs. A clang on mental health is also impacted by the persistent itching, aching, and stiffness of the skin, in addition to physical embarrassment. Furthermore, the noticeable nature of ichthyosis can cause the development of emotions of self-consciousness and disgrace, obscuring social communications and associations. The trials tackled by patients are further intensified when the patients try to cope with the difficulties of wide-ranging skincare procedures and steering a world planned without attention to their exceptional requirements (Khan & Khan, n.d.; Kharkiv National Medical University *et al*., 2023; Le Henaff *et al*., 2023; Moledina *et al*., 2023; Montgomery & Thompson, 2018).

3.3 Advocacy Groups: Authorizing Patients

Advocacy groups are fundamental to the authorization of persons with Ichthyosis that defend their goals and strengthen their speeches. Irreplaceable care, possessions, and society for patients and families suffering from the disorder are provided by establishments such as the Foundation for Ichthyosis & Related Skin Types (FIRST). These establishments initiate advancement in accepting, handling, and eventually treating Ichthyosis by creative activities extending from informative outreach to policy encouragement. These organizations work as catalytic agents for modification, joining the break between patients, healthcare workers, scientists, and officials (*Advocacy | Foundation for Ichthyosis & Related Skin Types (FIRST)*, n.d.) and also provide medical genetics services (Sajid S et al., 2025). These administrations motivate advancement in research, progressive contact with care, and increase consciousness about Ichthyosis by uplifting patient speeches and encouraging their requirements. Patients are empowered by the advocacy establishments to convert into dynamic contributors in their upkeep and mediators of modification in their societies through combined corporations and strategic creativities (Bhattacharya *et al*., 2019). Molecular treatment of Ichthyosis has become favorable due to the latest improvements in pathogenesis-based treatments such as gene therapy and enzyme replacement therapy, which are showing potential. The usage of repurposed and biologic medicines has also been discovered by scientists to address the provocative dysregulation perceived in some types of Ichthyosis (Joosten *et al*., 2022).

Table 2: Patient-Oriented Care Model for Ichthyosis

Aspect	**Importance**	**Role of Advocacy**	**Impact on Patients**	**References**
Patient Priorities	Aligning treatment objectives with patient priorities	Advocacy groups promote patient-centered care	Psychological suffering, Self-consciousness & Shame	Aguiar *et al*., 2021; Khalfin *et al*., 2019
Patient Education	Providing patients with accurate information	Advocacy groups offer educational resources	Limited social interactions & Social segregation	Ozkaynak *et al*., 2019
Patient Support	Offering emotional support and social connections	Advocacy groups provide a sense of community	Ectropion, Eclabium & Heat intolerance	Konson *et al*., 2022
Patient Advocacy	Empowering patients to advocate for themselves	Advocacy groups amplify patient voices	Atopic diathesis & Growth retardation	Aguiar *et al*., 2021; Smyshlyaev *et al*., 2021
Medical Care	Providing medical treatment and management	Advocacy groups promote access to medical care	Respiratory distress & Sepsis	Aguiar *et al*., 2021; Khalfin *et al*., 2019
Psychosocial Care	Providing counseling and support	Advocacy groups offer psychosocial support	Anxiety, Depression & Social isolation	Ozkaynak *et al*., 2019; Konson *et al*., 2022
Social Care	Providing social support and connections	Advocacy groups promote social connections	Limited social interactions & Social segregation	Konson *et al*., 2022

3.4 The Spirit of Patient-Oriented Care

Discrete patient requirements, encircling physical, demonstrative, and social sustenance, are fulfilled by healthcare, which is enabled by patient-oriented care (Aguiar *et al*., 2021; Khalfin *et al*., 2019; Smyshlyaev *et al*., 2021). Crucial constituents like Custom-made treatment strategies, patient instruction, and contact with funding groups are intended to improve the general worth of life (Ozkaynak *et al*., 2019). Developing reliance between healthcare benefactors and patients' operative interactions is essential. Ethnically skilled interaction, compassion, and clear data endowment reinforce the patient-provider association, enlightening the patient's understanding (Konson *et al*., 2022). A comprehensive model for patient-oriented care for Ichthyosis, highlighting the importance of various aspects and the role of advocacy groups, is provided in **Table 2**.

3.5 A Complete Interpretation of Ichthyosis Care

A complete interpretation reflects the societal, emotional, and physical features of Ichthyosis. Due to itching, noticeable scaling, and functional restrictions, patients practice lessened worth of life (Butala *et al*., 2023). The basis of complete maintenance is formed by participating in medicinal and psychosocial care, avoiding dishonor, and encouraging patient-orienteers. The impression of Ichthyosis spreads far away outside the boundaries of dermatological indications, pervading every phase of patients' everyday lives (Murashkin *et al*., 2022; Sun *et al*., 2022). In provision of permanent sympathetic attention, health workers play a decisive part as there is at present no ultimate therapy for Ichthyosis (Walsh *et al*., 2023). The patients feel support in shared practices and cooperative authorization through societal care and sponsorship. Sponsorship groups induce a dynamic part in confirming that patients' opinions are perceived and their requirements are discussed by promoting a sense of consideration and belonging.

3.6 Encounters and Chances

Patients suffering from Ichthyosis come across several encounters, which include restricted contact with specific care, psychosocial influence, physical distress, and economic loads (Butala *et al*., 2023; Cortés *et al*., 2023). Nevertheless, advancement opportunities are present, like patient sponsorship groups, therapeutic patient training, telemedicine, and holistic care methodologies. For improving care and sustenance for individuals having Ichthyosis combined struggles and inventive approaches propose hopeful possibilities (Hemrajani *et al*., 2022; Walsh *et al*., 2023).

3.7 Directions for the Future

In accurate medicines, modified methodologies, patient-reported results, psychosocial maintenance agendas, sponsorship, telemedicine, and research partnerships lies the future of Ichthyosis care. By implementing these improvements and listing patient viewpoints, the healthcare society can initiate significant advancements in the identification, treatments, and care systems for persons with Ichthyosis.

4 CONCLUSION

Ichthyosis is a complicated skin disorder characterized by abnormal keratinization that needs a complete treatment plan taking into account physical, emotional, and social factors. Healthcare workers need to understand the specific needs of people with Ichthyosis and give them power through advocacy groups. Gene therapy and enzyme replacement therapy are two molecular treatments that can make treatment better. But to fully understand Ichthyosis care, we need to look at the social, emotional, and physical aspects, stressing how important patient-centered care and support are. This all-around method makes sure that people with Ichthyosis get full care.

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