Psychological Interventions for Enhancing Adaptation in Children with Xeroderma Pigmentosum (Children of the Moon)

التدخلات النفسية لتعزيز التكيف لدى الأطفال المصابين بجفاف الجلد المصطبغ (أطفال القمر)

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Abstract Xeroderma Pigmentosum (XP), commonly known as "Children of the Moon," is a rare genetic disorder characterized by defective DNA repair following exposure to ultraviolet (UV) radiation. As a result, affected children experience extreme photosensitivity and face a high risk of developing early skin cancers. Beyond its physical manifestations, XP has important psychological and social consequences for both children and their families. Daily photoprotection measures, social restrictions, and visible effects of the disease may contribute to emotional distress, social isolation, low self-esteem, and difficulties in school and peer relationships, although previous literature has mainly focused on the dermatological and genetic dimensions of XP, limited attention has been given to the psychological adjustment of affected children and the role of family-centered psychological support. This highlights the need to consider psychological care as an essential component of multidisciplinary disease management; Accordingly, this theoretical paper explores the psychological and familial challenges associated with XP and examines the contribution of psychological support within multidisciplinary care approaches. The paper discusses the psychosocial impact of the disorder on children and caregivers, reviews previous studies related to psychological adaptation and family support, and highlights the role of coordinated care involving dermatology, genetics, ophthalmology, neurology, and mental health services. The paper concludes that integrating psychological and family-centered interventions into multidisciplinary care can improve coping capacities, treatment adherence, and long-term quality of life among children with XP and their families.

- Keywords: Xeroderma Pigmentosum, Psychological Interventions, Children of the Moon

- الملخص: يُعرف اضطراب جفاف الجلد المصطبغ (XP) باسم "أطفال القمر"، وهو اضطرابًا وراثيًا نادرًا يتميز بخلل في إصلاح الحمض النووي (DNA) بعد التعرض للأشعة فوق البنفسجية .(UV) ونتيجة لذلك، يعاني الأطفال المصابون من حساسية مفرطة تجاه الضوء، ويواجهون خطرًا مرتفعًا للإصابة المبكرة بسرطانات الجلد. وإلى جانب مظاهره الجسدية، يخلّف المرض آثارًا نفسية واجتماعية مهمة على الأطفال وأسرهم. فإجراءات الحماية اليومية من الضوء، والقيود الاجتماعية، والآثار الظاهرة للمرض قد تساهم في حدوث ضغوط انفعالية، وعزلة اجتماعية، وانخفاض تقدير الذات، وصعوبات في العلاقات المدرسية وعلاقات الأقران، ورغم أن الأدبيات السابقة ركزت أساسًا على الجوانب الجلدية والوراثية لمرض جفاف الجلد المصطبغ، فإن الاهتمام

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بالتكيف النفسي للأطفال المصابين ودور الدعم النفسي المتمركز حول الأسرة ظل محدودًا، مما يبرز أهمية إدماج الرعاية النفسية ضمن التدبير العلاجي متعدد التخصصات. ، وانطلاقًا من ذلك، تسعى هذه الدراسة النظرية للكشف عن التحديات النفسية والأسرية المرتبطة بالمرض، وتبحث في إسهام الدعم النفسي ضمن مقاربات الرعاية متعددة التخصصات. كما تناقش التأثيرات النفسية والاجتماعية للاضطراب على الأطفال ومقدمي الرعاية، وتستعرض الدراسات السابقة المتعلقة بالتكيف النفسي والدعم الأسري، وتبرز دور الرعاية المنسقة التي تشمل الأمراض الجلدية، والوراثة، وطب العيون، وطب الأعصاب، وخدمات الصحة النفسية. وتخلص الورقة إلى أن دمج التدخلات النفسية والأسرية ضمن الرعاية متعددة التخصصات يمكن أن يسهم في تحسين التكيف، والالتزام بالعلاج، وجودة الحياة على المدى الطويل لدى الأطفال المصابين بجفاف الجلد المصطبغ وأسرهم.

- **الكلمات المفتاحية:** أطفال القمر ، التدخلات النفسية، اضطراب جفاف الجلد المصطبغ.

- Introduction:

Xeroderma Pigmentosum (XP) is a rare autosomal recessive genetic disorder caused by defects in the nucleotide excision repair (NER) pathway, which is responsible for repairing ultraviolet (UV)-induced DNA damage. The failure of this mechanism results in extreme photosensitivity, early-onset cutaneous damage, and a markedly increased risk of skin malignancies at a young age. In severe cases, XP may also involve ocular complications and progressive neurological deterioration, reflecting its multisystemic and degenerative nature (Lehmann et al., 2011).

Beyond its biomedical basis, XP has been increasingly recognized as a condition with profound psychological and social implications. Previous studies have shown that children with XP experience stigma, reduced quality of life, and significant social restriction due to continuous photoprotection and environmental avoidance (Hawkins et al., 2012; Anderson et al., 2017). These constraints significantly interfere with normal developmental processes, including peer interaction, school participation, and identity formation, thereby placing XP within a broader psychosocial vulnerability framework rather than a purely dermatological condition.

In parallel, emerging evidence highlights that the burden of XP extends to the family system. Caregivers are required to maintain constant vigilance, restructure daily routines, and ensure strict adherence to protective measures, which often leads to chronic stress and emotional exhaustion (Kuhlthau et al., 2011). Anderson et al. (2019) further demonstrate that families adopt different coping patterns, ranging from

normalization strategies to restrictive avoidance, each carrying distinct psychological consequences for both the child and the family unit. These findings reinforce the necessity of understanding XP as a family-centered condition rather than an isolated pediatric disorder.

Despite these insights, the literature remains predominantly biomedical, with a strong focus on genetic mechanisms, dermatological outcomes, and oncological risk. Psychological and social dimensions, although acknowledged, are often treated as secondary outcomes or examined indirectly within broader dermatological populations (Fournier et al., 2023; Roje et al., 2016). This reveals a clear conceptual and empirical gap in understanding the specific lived psychological experience of children with XP, as well as the mechanisms through which family dynamics influence adaptation and coping processes.

Furthermore, although multidisciplinary care is widely recommended in rare diseases, its practical integration in XP management remains inconsistent. While dermatological, genetic, neurological, and ophthalmological follow-up are well established, psychological care is often underrepresented or applied in a non-systematic manner. Existing literature suggests potential benefits of cognitive-behavioral therapy, narrative interventions, and peer support systems; however, these approaches are largely extrapolated from general dermatological populations rather than being XP-specific, limiting their contextual applicability (Christensen & Jafferany, 2023; Cadmus et al., 2018).

Accordingly, this theoretical review aims to critically examine the psychological, social, and familial dimensions of Xeroderma Pigmentosum within a multidisciplinary framework. It specifically explores how existing literature conceptualizes psychosocial adaptation in XP, identifies gaps between biomedical dominance and psychological neglect, and evaluates the role of family-centered and behavioral interventions in supporting coping, adherence, and quality of life. Ultimately, the paper argues that

psychological care should not be considered an adjunctive component, but rather an essential pillar in the comprehensive and long-term management of XP.

- Literature Review: Psychological and Psychosocial Aspects of Xeroderma Pigmentosum

The literature on Xeroderma Pigmentosum (XP) consistently demonstrates that the condition extends beyond its genetic and dermatological basis to include profound psychological and social consequences. However, the depth and interpretation of this impact vary across studies depending on their methodological orientation.

Research using quantitative approaches, such as Hawkins et al. (2012), reports a moderate impact of XP on children's quality of life using standardized instruments. While these findings provide useful clinical benchmarks, they risk underestimating the real burden of the disease, as numerical classifications do not fully capture the daily constraints imposed by strict photoprotection, environmental avoidance, and social restriction. In contrast, qualitative evidence offers a more nuanced perspective. Anderson et al. (2017) show that individuals with XP often experience stigma from early childhood, particularly due to visible protective behaviors such as specialized clothing and sun avoidance strategies. Importantly, their findings suggest that stigma is not a static experience but one that becomes internalized over time, shaping identity formation and self-esteem. However, the generalizability of these findings remains limited due to the small, context-specific sample.

Similarly, Roje et al. (2016) examine psychosocial functioning in children with chronic skin conditions and highlight common outcomes such as low self-esteem, body image concerns, and anxiety about the future. While this comparison broadens understanding, it also risks diluting the specificity of XP, as the disorder imposes far more severe and lifelong environmental restrictions than most dermatological conditions. This indicates a limitation in the current literature, where XP is sometimes conceptualized within broader categories without sufficient attention to its unique severity.

A key conceptual advancement is provided by Mitchell (2018), who proposes a bidirectional model between psychological health and dermatological symptoms. According to this model, emotional distress can exacerbate physical symptoms, while visible symptoms intensify psychological burden. This cyclical relationship is particularly relevant in XP, where chronic stress may indirectly influence disease management through reduced adherence to strict photoprotection routines. However, while theoretically valuable, this model remains general and does not fully address the extreme environmental dependency that defines XP.

Fournier et al. (2023) further emphasize that rare genetic skin diseases are associated with significant psychosocial burden, including social isolation and stigma. Nevertheless, their analysis does not clearly distinguish whether these outcomes are driven by the rarity of the disease itself or by its functional severity, leaving an important conceptual ambiguity unresolved. In a similar vein, Christensen and Jafferany (2023) highlight the importance of integrating psychological and dermatological care in chronic skin diseases. Although their contribution supports a biopsychosocial understanding of XP, the discussion remains largely descriptive and does not provide detailed mechanisms explaining how psychological distress develops and persists in this specific condition.

In terms of psychological interventions, the literature primarily focuses on cognitive-behavioral therapy (CBT), narrative approaches, and peer support systems. CBT is consistently identified as effective in reducing anxiety and improving coping strategies in dermatological populations (Christensen & Jafferany, 2023; Cadmus et al., 2018). However, most evidence is derived from general skin condition samples rather than XP-specific populations, which limits the direct applicability of these findings. Naidoo and Williams (2013) propose storytelling therapy as an alternative approach that allows children to reconstruct their illness experience in a more adaptive narrative form. While conceptually promising, this intervention still lacks strong empirical validation in XP contexts. Additionally, Hawkins et al. (2012) highlight the potential

benefits of online support groups in reducing feelings of isolation among individuals with XP. Despite these encouraging findings, the long-term effectiveness and developmental differences in response to such interventions remain underexplored.

Family functioning emerges as a central determinant of adaptation to XP across multiple studies. Anderson et al. (2019) identify two main coping patterns within families: normalization strategies and avoidance strategies. While this distinction is useful for understanding behavioral adaptation, the literature does not provide clear evidence regarding the long-term psychological or clinical effectiveness of either approach. Kuhlthau et al. (2011) further emphasize that caregiver burden is strongly associated with parental mental health outcomes in pediatric chronic illness. This finding reinforces the view that XP should be understood not only as an individual condition but as a family-centered challenge. However, structured psychological interventions targeting caregiver burden remain insufficiently developed in this field. Mitchell (2018) also supports the need for family-based psychological care, yet does not provide operational frameworks specific to XP.

Regarding clinical management, there is strong consensus in the literature on the importance of multidisciplinary care involving dermatology, genetics, neurology, ophthalmology, and psychology. Andrade and Castelo-Soccio (2019) emphasize the need for early psychological screening in pediatric dermatology patients to identify emotional and behavioral difficulties. However, implementation in clinical practice remains inconsistent. Similarly, Christensen and Jafferany (2023) advocate for integrated psychodermatology models, but practical guidelines for coordinating such care in rare diseases like XP are still limited.

Overall, the literature presents XP as a complex condition that cannot be fully understood through a purely biomedical lens. However, three key gaps remain evident. First, there is a methodological gap between quantitative and qualitative approaches, leading to discrepancies between measured impact and lived experience. Second, there is an intervention gap, as most psychological strategies are adapted from other

conditions rather than specifically designed for XP. Third, there is an integration gap, as medical, psychological, and family-based perspectives are often treated separately rather than within a unified care model. These limitations highlight the need for a more integrated biopsychosocial framework specifically tailored to XP that bridges clinical care with psychological and social realities.

Understanding Xeroderma Pigmentosum requires examining not only its biological basis but also the broad clinical and psychosocial consequences associated with the disorder. The following section provides an overview of the major medical manifestations of XP and their impact on children's psychological and social adjustment**.**

1- Clinical and Psychosocial Features of XP:

XP is associated with a wide spectrum of clinical manifestations that affect several body systems and significantly influence the child's daily functioning and quality of life. Understanding these manifestations is essential for appreciating the complexity of care required for affected children.

1.1- Clinical overview: Xeroderma Pigmentosum (XP) is a rare autosomal recessive disorder resulting from pathogenic variants in genes involved in the nucleotide excision repair (NER) pathway. This pathway plays a critical role in repairing ultraviolet (UV)-induced DNA damage, particularly thymine dimers and other photoproducts caused by exposure to UV radiation. Failure of this mechanism leads to the hallmark clinical features of XP, which include extreme photosensitivity, early freckling, pigmentary changes, and a dramatically increased predisposition to cutaneous malignancies such as basal cell carcinoma, squamous cell carcinoma, and malignant melanoma at an unusually young age (DiGiovanna & Kraemer, 2012; p.138).

The dermatological manifestations usually begin in early childhood, often within the first two years of life. Initial signs may include persistent sunburns, xerosis, atrophic skin changes, and mottled pigmentation. Children may develop actinic keratoses, solar lentigines, and early photoaging that mimics the appearance of elderly skin. Without

strict photoprotection, the cumulative risk of non-melanoma skin cancer before the age of 10 is significantly elevated, underscoring the need for early diagnosis and aggressive preventive strategies (Sarasin, 2019; p.84).

Neurological complications represent a critical dimension of XP, with certain complementation groups (such as XP-A, XP-D, and XP-G) associated with progressive neurodegeneration. Clinical features may include sensorineural hearing loss, cognitive decline, diminished reflexes, and progressive motor dysfunction. The underlying neuropathology is believed to result from the defective repair of oxidative DNA damage in neuronal cells, leading to apoptosis and progressive neurological impairment (Anttinen et al., 2008, p. 131). These neurological features substantially worsen prognosis and quality of life, often leading to reduced life expectancy in affected individuals.

Ophthalmological involvement is another hallmark of XP. Patients frequently develop photophobia, conjunctivitis, keratitis, and corneal opacities. Chronic exposure to UV light without protection can accelerate ocular surface damage, increasing the risk of vision loss. Specialized ophthalmological monitoring, along with protective eyewear, is therefore essential in comprehensive management (Bradford et al., 2011; p.168).

Beyond dermatological, neurological, and ophthalmological domains, systemic manifestations have also been reported in subsets of XP patients. These include dental abnormalities, endocrine disturbances, and, in rare cases, internal neoplasms. The variability in clinical phenotype reflects genetic heterogeneity across at least eight distinct complementation groups (XP-A through XP-G, and XP-V for the variant type), each linked to mutations in different genes critical for DNA repair (Cleaver et al., 2009; p. 756).

In summary, XP is a multisystem disorder that extends far beyond photosensitivity. The wide spectrum of clinical features- ranging from severe dermatological damage and early-onset skin cancers to progressive neurological decline- necessitates a multidisciplinary management approach. Early recognition,

rigorous photoprotection, ongoing dermatological surveillance, and psychosocial support for patients and families remain the cornerstones of care. Advances in molecular diagnostics and gene-specific understanding are paving the way for more personalized interventions and potential future therapies (Lehmann et al., 2011; p.70).

Beyond its physical complications, XP creates substantial psychological and social challenges for both children and their families. These consequences often emerge from the continuous need for protection, social restrictions, and the emotional burden associated with living with a rare chronic condition.

1-2- Psychosocial consequences: Rare genetic skin diseases such as Xeroderma Pigmentosum (XP) carry a profound psychosocial burden in addition to their physical consequences. Research demonstrates that visible skin disorders, particularly those associated with strict lifestyle restrictions, are strongly correlated with diminished quality of life, heightened social isolation, and increased vulnerability to stigma and discrimination (Fournier et al., 2023, p. 5). For children with XP, the necessity of constant photoprotection and avoidance of daylight environments can severely restrict normal developmental experiences, leading to reduced school attendance, diminished participation in peer-related activities, and delayed or disrupted social identity formation (Ridora et al., 2024, p. 3). These constraints often translate into lower self-esteem and heightened feelings of difference from peers, which can become risk factors for internalizing symptoms such as anxiety and depression.

The family context plays a central role in shaping these psychosocial outcomes. Parents of children with XP must frequently reorganize daily schedules to minimize sun exposure, which often requires limiting outdoor activities, modifying travel routines, and instituting complex protective measures such as UV-shielded clothing and home adaptations (UNSW Behavioural Sciences Unit, n.d.). These adjustments, while medically essential, can create emotional strain within families. Caregivers often report high levels of stress and fatigue, associated both with the burden of constant vigilance and with the uncertainty of disease progression. This aligns with findings in broader

pediatric chronic illness research, where family burden is strongly predictive of parental mental health outcomes (Kuhlthau et al., 2011, p. 243).

Adherence to photoprotection is itself shaped by psychosocial dynamics. (Walburn et al. 2019, pp. 3–4) highlight those protective behaviors, such as wearing protective clothing or applying sunscreen, are not only medical but also behavioral practices influenced by habit strength, family routines, and perceived vulnerability. Children who internalize these routines as automatic behaviors tend to display higher adherence, while families who struggle with consistency often experience conflict, guilt, and blame. (Sarkany et al. 2022, pp. 1097–1099) further note that low adherence not only exacerbates medical risk but also fuels parental anxiety, establishing a bi-directional stress cycle: poorer adherence increases parental distress, which in turn reduces the family's capacity to enforce consistent protective routines.

Moreover, psychosocial consequences extend beyond the individual child and immediate caregivers. Siblings may also experience feelings of neglect due to the disproportionate parental attention required for the affected child, or frustration over lifestyle limitations imposed on the entire family unit. Such dynamics can foster sibling rivalry, resentment, or overprotectiveness, echoing patterns observed in other rare pediatric conditions (. At the community level, lack of public awareness of XP may contribute to stigmatization, as visible protective clothing or avoidance of daylight activities may mark children as "different," further amplifying social exclusion.

Taken together, these psychosocial consequences highlight the need for integrated psychological interventions targeting both individual coping and family resilience. Interventions should include psychoeducation, parental stress management, school-based inclusion strategies, and peer sensitization programs. Addressing psychosocial burdens is as crucial as medical management, as improved psychological well-being contributes to better adherence, more cohesive family functioning, and ultimately improved health outcomes for children with XP.

Given the multidimensional impact of XP, psychological support represents an essential component of comprehensive care. The psychologist plays an important role in helping children and families adapt emotionally, behaviorally, and socially to the demands of the disorder.

2- Role of the Psychologist in Care for Children with XP:

The management of XP requires close collaboration between multiple healthcare professionals in order to address the diverse medical and psychosocial needs of affected children. Within this framework, psychological care contributes to improving both emotional well-being and treatment adherence.

2.1- Multidisciplinary context: Effective care for Xeroderma Pigmentosum (XP) requires a multidisciplinary approach that integrates dermatology, genetics, ophthalmology, neurology, and psychology. Because of the complex and multi-dimensional nature of the disorder, XP is no longer regarded solely as a dermatological condition but as a syndrome demanding comprehensive care that extends beyond the medical domain (Marshall et al., 2024, p. 18). Clinical research has shown that combining these specialties within a collaborative model contributes to better health outcomes for children while also reducing the logistical and emotional burdens families face when navigating fragmented care systems (Hirsch et al., 2020, p. 442).

Psychology is an essential component within this multidisciplinary framework, as psychological services are increasingly recognized as integral to holistic care for rare pediatric conditions (XP Family Support, n.d.). Psychologists contribute in several domains: first, through comprehensive psychological assessment covering mental health, social adjustment, and quality of life; second, through therapeutic interventions such as cognitive-behavioral therapy (CBT), which supports children in managing anxiety and depression associated with lifestyle restrictions (Thompson & Kent, 2021, p. 63). Psychologists also design behavioral strategies to improve adherence to photoprotection, embedding sun-protection routines into daily life and training families in positive reinforcement techniques (Walburn et al., 2019, p. 4).

Moreover, psychologists extend their work to systemic family interventions. The family unit represents the core determinant of whether medical and behavioral recommendations succeed in practice. Family counseling sessions focused on stress management, parental role distribution, and sibling coping skills have been shown to reduce household tension and improve emotional cohesion (Kuhlthau et al., 2011, p. 243). Integrating psychological support within multidisciplinary care strengthens family resilience and reduces the risk of caregiver burnout, which is particularly prevalent in families facing rare pediatric conditions (Chow et al., 2024, p. 13).

On an organizational level, specialized hospitals and rare disease centers increasingly employ **joint clinics**, where dermatologists, geneticists, ophthalmologists, neurologists, psychologists, and social workers collaborate to design unified care plans for children with XP (Hirsch et al., 2020, p. 445). Such models not only facilitate access to medical and psychosocial services but also reduce financial and logistical barriers for families who often must travel long distances to seek specialized care.

The integration of psychology into multidisciplinary care also extends to health policy. Patient advocacy groups, including XP Family Support, emphasize the importance of ensuring that psychological and social support are embedded alongside medical treatment in national rare disease strategies (XP Family Support, n.d.). This reflects a paradigm shift toward **biopsychosocial models of health**, which consider biological, psychological, and social dimensions as equally important in the care of complex pediatric conditions (Marshall et al., 2024, p. 22).

Effective psychological intervention begins with a comprehensive assessment that considers the child's emotional functioning, family environment, developmental needs, and medical challenges associated with XP.

2-2- Assessment and Formulation: Psychological assessment in the context of XP (xeroderma pigmentosum) requires a nuanced approach that considers the interplay between medical, cognitive, and psychosocial domains. Children living with XP often undergo frequent medical evaluations, but psychological assessments remain essential

to identify anxiety disorders, depressive symptoms, post-traumatic stress responses, and difficulties with self-concept arising from visible differences (Walburn et al., 2019). Developmental assessments help determine whether psychosocial stressors interfere with milestones such as peer relationships, school engagement, or independence. A comprehensive clinical formulation integrates the child's medical risk profile, family dynamics, cognitive functioning, and cultural context to inform tailored interventions (Streisand & Mednick, 2018). Assessment should also include measures of parental stress and caregiver burden, as families often report heightened anxiety and emotional exhaustion due to the vigilance required for photoprotection (Fournier et al., 2023, p. 412). Sibling adjustment is another critical domain, as brothers and sisters may experience secondary distress or feelings of neglect.

Psychological interventions for children with XP should aim not only to reduce distress but also to strengthen coping skills, social adjustment, and long-term adaptation to the disease.

2-3-Individual and Group Interventions: Evidence-based interventions for children with chronic illnesses such as XP emphasize cognitive-behavioral therapy (CBT) adapted for medical contexts. CBT can reduce avoidance behaviors, manage illness-related anxiety, and enhance adherence to medical regimens (Rohan et al., 2020, p. 527). Exposure-based strategies help children confront fears of stigma or social rejection, while cognitive restructuring addresses maladaptive illness beliefs (e.g., "I will never be able to live normally"). Problem-solving skills training supports families in managing daily barriers to photoprotection, such as peer pressure or school participation. Group interventions, including peer support groups and structured psychosocial education sessions, foster resilience by normalizing experiences and reducing isolation. Research on rare diseases shows that online peer communities significantly enhance well-being, particularly in conditions where children cannot safely engage in many public settings (Eurordis, 2022; XP Family Support, n.d.).

Maintaining strict photoprotection routines can be psychologically and behaviorally demanding for children and families. Behavioral strategies therefore play a crucial role in supporting treatment adherence and reducing family stress.

2-4-Behavioral Strategies for Adherence: Behavioral psychology offers powerful tools to strengthen adherence to photoprotection routines. Strategies such as habit formation, visual schedules, and reinforcement systems can transform protective behaviors into automatic routines (Sarkany et al., 2022, p. 117). For instance, linking sunscreen application to daily transitions (e.g., brushing teeth before leaving home) increases consistency. Psychologists can introduce behavioral contracts with older children and motivational interviewing with families to enhance commitment and reduce resistance (Walburn et al., 2019). Research shows that adherence is not merely a function of knowledge but is shaped by family cohesion, caregiver modeling, and environmental facilitators (Luo et al., 2024). Sustained non-adherence, however, can trigger a feedback loop of poorer clinical outcomes, escalating parental anxiety, and increased family stress.

Family functioning strongly influences the child's ability to adapt to XP and maintain protective behaviors over time. For this reason, family-centered care has become increasingly important in the management of chronic pediatric conditions.

3-The Role of Family in Recovery and Adaptation:

3.1- Family as Primary Support System: Families are the cornerstone of adaptation for children with XP, providing both practical and emotional scaffolding. Caregivers manage complex routines involving protective clothing, specialized eyewear, and sunscreen application multiple times per day. The effectiveness of this support depends on caregiver self-efficacy and family functioning (Luo et al., 2024, p. 981). Families with higher levels of cohesion and open communication are more likely to maintain adherence and buffer the psychological effects of social restriction. Importantly, advocacy within school and healthcare systems also falls primarily to families,

highlighting the need for systemic family empowerment programs (Marshall et al., 2024).

3-2-Emotional Climate and Parental Coping: The emotional climate within families can either buffer or exacerbate stress. Parental anxiety- especially fear of early skin cancer- may lead to restrictive parenting, inadvertently hindering the child's autonomy and social growth (Morgan et al., 2019). Psychological interventions that address catastrophic thinking and support adaptive coping improve both parent and child outcomes. Psychoeducational programs teaching balanced caregiving, relaxation techniques, and problem-solving skills can reduce caregiver burnout and foster healthier family environments (Kuhlthau et al., 2011).

3-3-Sibling Experiences and Broader Family Effects: The needs of siblings often remain overlooked in clinical care. Siblings of children with XP may experience role changes, emotional neglect, or heightened anxiety about their brother's or sister's prognosis (Fournier et al., 2023, p. 418). Providing siblings with accurate information, opportunities for expression, and supportive peer networks helps mitigate these risks. Family interventions that include siblings in psychoeducational and emotional support programs contribute to overall family resilience (Fournier et al., 2023). Adaptation to XP is also influenced by cultural beliefs, financial resources, and environmental conditions, which may either facilitate or complicate long-term disease management.

3-4-Cultural, Socioeconomic, and Geographical Moderators: The feasibility of strict photoprotection varies greatly depending on family resources, cultural norms, and environmental factors. Families in tropical or resource-limited settings face significant challenges, including high temperatures that make protective clothing uncomfortable, limited access to dermatological care, and economic constraints on acquiring protective equipment (Ridora et al., 2024, p. 233). Cultural beliefs about illness and stigma may also influence adherence and the child's social participation. Psychologists must therefore adapt interventions to align with cultural practices and socio-economic realities, integrating community-based and telehealth solutions where possible.

3-5-Intervention Models and Evidence: Family-centered care (FCC) emphasizes collaboration between families and healthcare providers. Empirical reviews show that FCC interventions improve satisfaction, engagement, and quality of life for children with chronic illnesses, Psychologists play a pivotal role by aligning medical recommendations with family priorities and by fostering collaborative communication within care teams. Integrated psychological services, embedded within pediatric dermatology and genetics clinics, allow for real-time assessment and immediate therapeutic interventions. These models reduce fragmentation of care and enhance adherence outcomes (Marshall et al., 2024). Systemic family therapy and parent management training—though not yet studied extensively in XP- demonstrate strong evidence across pediatric chronic illness populations for reducing distress and improving functional outcomes (Hogue et al., 2021).

Translating psychological knowledge into practical strategies is essential for improving everyday functioning and reducing the psychosocial burden experienced by children with XP and their families.

4-Practical Clinical Strategies for Psychologists and Families:

Effective strategies begin with biopsychosocial assessment and individualized care planning, addressing not only the child's developmental needs but also family functioning and socio-economic context. Psychoeducation, delivered in age-appropriate formats, builds understanding and motivation for adherence. Visual habit trackers, environmental cues, and daily routines increase consistency in photoprotection. Addressing stigma and social isolation requires school liaison work, peer support initiatives, and training in coping narratives. For parents, targeted interventions to strengthen caregiver self-efficacy, reduce anxiety, and redistribute caregiving tasks foster resilience. Finally, telehealth platforms expand access to psychological care, while collaborations with rare disease advocacy groups enhance social connectedness and resource availability.

The previous sections demonstrate that XP affects multiple dimensions of children's and families' lives, making integrated psychological and medical support essential for long-term adaptation and well-being.

4-Conclusion:

This theoretical review set out to examine the psychological, social, and familial dimensions of Xeroderma Pigmentosum (XP), with a particular focus on the place of psychological care within multidisciplinary management. In relation to these objectives, the reviewed literature leads to several consolidated findings.

First, the evidence consistently shows that XP cannot be understood solely as a genetic or dermatological disorder. Beyond its biological mechanisms, the condition has a sustained psychological impact on children, mainly expressed through anxiety, social withdrawal, reduced self-confidence, and difficulties in peer integration. These outcomes are closely linked to the chronic lifestyle restrictions imposed by strict photoprotection, which limit normal developmental experiences and shape identity formation from early childhood.

Second, the review confirms that the burden of XP extends significantly to the family system. Caregivers are required to maintain continuous vigilance and reorganize daily life around environmental avoidance, which often results in emotional exhaustion and elevated stress levels. At the same time, family functioning appears to be a key moderating factor in adaptation, as cohesion, communication, and coping patterns directly influence both adherence to treatment and the child's psychological adjustment.

Third, the analysis of existing literature highlights a clear imbalance between biomedical dominance and psychological underrepresentation. While genetic, dermatological, and neurological aspects of XP are well documented, psychosocial dimensions remain fragmented, often studied indirectly or within broader dermatological populations. This limits the understanding of the specific lived

experience of children with XP and creates a gap between clinical knowledge and psychological reality.

Fourth, although different psychological interventions- such as cognitive-behavioral therapy, narrative approaches, and peer support- show promising effects in chronic illness populations, their direct applicability to XP remains limited. Most interventions are not specifically adapted to the unique and lifelong environmental constraints of the disorder, which reduces their contextual precision and effectiveness.

In light of these findings and in direct relation to the objectives of this study, several recommendations emerge. It is first necessary to develop XP-specific psychological intervention models that take into account the extreme nature of photoprotection demands and their impact on daily functioning. Second, psychological care should be systematically integrated into multidisciplinary teams from the moment of diagnosis, rather than being considered a secondary or optional service. Third, greater emphasis should be placed on family-centered interventions, particularly those targeting caregiver stress, sibling adjustment, and family communication patterns, as these are central to long-term adaptation. Finally, future research should adopt more qualitative and longitudinal designs in order to capture the evolving psychological experience of children with XP and their families in real-life contexts.

Overall, the findings of this review align clearly with its initial aim: they demonstrate that effective management of XP requires moving beyond a purely biomedical framework toward a fully integrated biopsychosocial model, where psychological care is not an adjunct, but a core component of long-term treatment and quality of life.

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