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Evaluation of quality of life in parents of children with genetic diseases: a multifactorial analysis (Rabat), Morocco

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Abstract

This research aims to assess the quality of life of parents of children with Genetic Diseases, with the aim of contributing to the improvement of their well-being. The present study involved sixty parents of children with Genetic Diseases. Their overall quality of life was assessed using the PAR-QoL questionnaire, which measures emotional and adaptive scores. In addition, health-specific quality of life (QoL) was quantified using the SF12, a shortened version of the SF-36, which assesses aspects of physical and mental health. Depressive and anxiety symptoms were assessed using the Hospital Anxiety and Depression Scale (HADS). Results obtained through the PAR-QoL score indicate an average quality of life among participants, with scores ranging from 2 to 3.5. HADS scores revealed a significant presence of anxiety and depressive symptoms among parents. SF12 scores reveal marked fatigue, both psychologically and physically. There was a higher prevalence of impaired scores among mothers than fathers, with 80% of female respondents. Research shows that the majority of parents faced with their child's Genetic Diseases face significant mental, physical, psychological and social challenges. These findings underline the imperative of adopting measures to support these families, to help them come to terms with the situation and preserve family equilibrium. This study highlights the need for comprehensive, integrated care for these families, to mitigate the impact of Genetic Diseases on their quality of life.

Keywords: Quality of life, Parents, Children, Genetic Diseases.

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1. Introduction

This academic study focuses on the quality of life of parents of children with Genetic Diseases at the Rabat Children's Hospital, a context hitherto little explored. Genetic Diseases, resulting from genetic mutations or alterations, vary widely in manifestation and severity, impacting physical development, metabolism, organ functions and the immune system. These diseases, which can be inherited or occur spontaneously, manifest themselves mainly in childhood and can progress to sometimes fatal outcomes. With over 6,000 known Genetic Diseases, they present a variety of symptoms and forms, considerably influencing the quality of life (QoL) of children and their families [1,2,3,4]. Genetic Diseases vary in severity, some being fatal from birth, while others require ongoing management. Symptoms in children can include developmental delays, intellectual impairments, or physical disabilities, affecting the functioning of specific organs or body systems [5]. The diagnosis of Genetic Diseases in a child imposes an emotional shock on parents, followed by overwhelming medical and financial responsibilities, generating feelings of guilt, sadness and stress. These complex situations require emotional support, relevant information about the disease, and practical assistance with day-to-day challenges. Worldwide, the prevalence of Genetic Diseases varies, with estimates indicating that 6% of newborns are born with genetic abnormalities [6]. In Europe, around 35 million people are affected, and in France, 3 million people are affected by Genetic Diseases, which are often rare and orphan [7]. In Morocco, the prevalence of Genetic Diseases varies, with diseases such as sickle cell anemia and thalassemia being relatively frequent [8]. Caring for a child with Genetic Diseases places a significant burden on parents, confronting them with physical, psychological, economic and social difficulties. They may experience feelings of guilt and helplessness, oscillating between denial of the disease and gradual acceptance of the situation [1]. The impact of Genetic Diseases on parents' QoL is profound, and their efforts to improve this quality of life can have positive

repercussions on themselves and their children [9]. The present study therefore aims to describe and analyze the QoL of parents of children with Genetic Diseases, focusing on the family, economic, psychological and socio-professional repercussions of their care pathway. This research is motivated by the lack of studies addressing this theme, particularly in the Moroccan context, where significant gaps remain in the understanding of these issues [10]. Quality of life (QoL) is a broad, multidimensional concept, underlining the difficulties of arriving at a single definition. Several authors have highlighted its subjective, global and dynamic nature, and its use in various fields [11,12]. QoL is studied in various fields, including sociology, economics and psychology, and has aroused growing interest among politicians, researchers and health and education professionals [13].

A multitude of definitions in the literature, including over 100 different definitions [14]. In 1993, for example, Patrick defined QoL as an individual's satisfaction in the areas of his life [15] including physical, social, economic and psychological well-being. KC Calman considers it to be the difference between an individual's hopes and expectations and current experience [16]. The international Conference of population and development defines en 1994 the QoL as an individual's perception of their place in life, in relation to their goals, expectations, norms and concerns, influenced by factors such as physical health, psychological state, level of independence, social relationships and environment [17]. Ulrike Ravens-Sieberer and al. consider QoL as a multidimensional concept including various physical, mental, emotional and social aspects [18]. Historically, the notion of QDV appeared in the United States in the 1960s, first in a political context with Lyndon Johnson, and then extended to various scientific fields [19]. In 1998, Corten described three conceptual currents of QDV: environmental, health-related, and encompassing all areas of life [20]. The assessment of QoL is complex and can be subjective or objective. Methods such as psychological interviews and psychometric questionnaires are used to measure QoL [21,22]. When it comes to the QoL of parents of sick children, several factors influence it, including the severity of the child's illness, care needs, financial resources, psychological factors, social support, and impact on daily life [23,24,25]. The importance of QoL assessment is underlined by its role in describing people's experiences, identifying changes over time, and its use as a criterion in therapeutic trials [26]. Studies conducted between 1990 and 2017 have shown the significant impact of Genetic Diseases on parents' QoL [27]. Genetic Diseases affects autonomy, physical abilities, affects, psychic life, social integration, and the burden of treatments [28]. Parents' QoL is assessed by taking into account physical, psychological, social and environmental dimensions, revealing the profound impact of Genetic Diseases on different aspects of their lives.

2. Materials and methods

2.1 Study setting

The investigation took place at the Children's Hospital in Rabat, Morocco, a renowned institution and the Kingdom's oldest pediatric center, offering a wide range of specialized medical and surgical care. Two departments of the hospital were specifically included in the study: the Pediatric Hematology and Oncology Service (SHOP) and the General Pediatrics, Diabetology, Endocrinology and Neurophysiology Department (P2).

2.2 Site Selection rationale

The Rabat Children's Hospital was chosen for its reputation for excellence in medical care, its privileged access to patients and its potential for fruitful interdisciplinary collaborations. The researchers' familiarity with this environment, due to previous internships, played a crucial role in facilitating access and communication with hospital staff.

2.3 Nature of the study

This research is descriptive in nature, aiming to assess and improve the quality of life of parents of children with Genetic Diseases.

2.4 Target population

The study focuses on parents of children under 16 years of age with Trisomy 21, Sickle Cell Disease, Beta thalassemia, Hemophilia, or MSP type I. Inclusion and exclusion criteria have been carefully defined to specify this specific population.

2.5 Sampling procedure

A total of 60 parents meeting the established criteria were interviewed. Data collection was carried out anonymously, with each parent responding individually to the questionnaire.

Valuation instruments used :

2.5.1 PAR-QOL (Parental Adjustment and Quality of Life)

A comprehensive questionnaire designed to assess the impact of childhood disorders on parents' quality of life, addressing emotional, social, and physical aspects [29]. The PAR-AR-QoL Questionnaire (parentalquality of life Arabic version): The PAR-AR-QoL questionnaire is the Arabic version of the French PAR-QoL questionnaire [30].

2.5.2 HAD (Hospital Anxiety and Depression Scale)

A bipartite scale for screening anxiety and depressive disorders, with subscales for anxiety and depression, consisting of seven items each [31].

2.5.3 SF-12 (Short Form Health Survey)

A concise version of the SF-36, measuring health-related quality of life through twelve questions covering physical and mental health. These instruments offer a comprehensive and nuanced assessment of families' well-being and quality of life, underlining their importance in both clinical and research contexts.

2.6 Translation and validation of tools

The tools have been adapted into Moroccan dialect following a rigorous translation and back-translation method, guaranteeing their relevance and validity in the Moroccan cultural context. The translation of the SF-12 standard format into dialectal Arabic has been validated [32]. This is the version we used in our study.

2.7 Statistical analysis

The data collected will be processed and analyzed using SPSS11.0 software. Analysis will include appropriate

statistical tests such as the Anova test for comparison of means and the linear correlation coefficient to examine variables influencing quality of life. A threshold of statistical significance was set at $p < 0.05$.

3. Results and Discussions

We obtained 60 responses out of a total of 90 questionnaires distributed to parents, i.e. 48 families who took part in this study. All responses were complete.

3.1. Description of the study population

3.1.1. Description of parents' demographic and socio-economic characteristics

Descriptive analysis of the parents' demographic and socio-economic characteristics (Table 1), revealed significant aspects that shape the participants' family and social context.

3.1.1.1 Parents' ages

Mothers have an average age of 46.58, compared with 37.25 for fathers, indicating a trend towards older mothers.

3.1.1.2 Consanguinity and Family Size

Consanguinity is reported in 33% of cases, while average family size is concentrated around 2 to 4 children, highlighting specific family patterns.

3.1.1.3 Knowledge of the disease and marital status

An overwhelming majority of parents (90%) are informed about the disease, and most (70%) are married, which could influence the dynamics of family support.

3.1.1.4 Education and employment

Parents are almost evenly divided between those in school (45%) and those not in school (55%), with a minority working in the civil service (23%), reflecting a variety of educational and professional backgrounds.

3.1.1.5 Income and Habitat

More than half of all families earn less than 3,000 dirhams a month, and the majority live in urban areas (72%), which has implications for access to resources and healthcare services.

3.1.1.6 Medical coverage

A large proportion of families (67%) benefit from AMO coverage, indicating a significant level of access to healthcare. These findings provide invaluable information for understanding the living environment of the families concerned, essential for developing health and support policies tailored to this population.

3.1.2. Description of the children's demographic, clinical, functional and therapeutic characteristics (n=60)

The data presented in Table 2 provides a summary of the demographic and clinical characteristics of sixty children.

Gender and age distribution: The study population shows a balanced gender distribution, with exact parity (50% girls, 50% boys).

The average age of the children was 9.67 years, with the majority concentrated between 7 and 12 years of age, suggesting a prevalence of the conditions studied in the primary school age group.

3.1.2.1 Sibling distribution

The data show a relatively uniform distribution of children according to family rank, with a slight predominance of younger children (45%).

3.1.2.2 Genetic pathologies

The diversity of Genetic Diseases within the sample is notable, with cases of B-Thalassemia (27%), sickle cell anemia (30%), hemophilia (15%), trisomy 21 (20%) and a category designated as 'MSI' (8%). This breakdown highlights the many facets of the clinical challenges encountered.

3.1.2.3 School status

In terms of education, a significant majority (67%) of children were integrated into the school system, underlining the importance of access to adapted education for this population. This academic synthesis of children's data raises critical demographic, clinical and educational issues, providing much-needed insight for health and education interventions and management strategies.

3.2. Impact of the child's pathology on the couple and the family

Table 3 provides a statistically significant overview of parents' psychological state, focusing on anxiety, depression, as well as physical and mental aspects of quality of life.

3.2.1. Psychological impact

HAD scores reveal high levels of anxiety and depression in parents, with means above the critical threshold of 10. Mothers showed slightly higher levels of anxiety (11.12 ± 2.3) and depression (11.75 ± 1.8) compared to fathers, differences that were statistically significant ($p < 0.01$).

3.2.2. Physical and mental quality of life

Analysis of SF12 scores shows better physical health in mothers (55.80 ± 16.64) than in fathers (42.03 ± 9.77), while mental health is more impaired in mothers (40.95 ± 15.95) than in fathers (43.1 ± 8.2), with significant differences in both cases ($p < 0.01$).

3.2.3. Emotional and adaptive scores

Although notable differences were observed in physical and mental health domains, parents' emotional and adaptive scores showed no statistically significant differences, indicating comparable levels of emotional well-being and coping skills. These findings underline a consequent psychological impact on parents, marked by high levels of anxiety and depression. The distinction in physical and mental quality of life between fathers and mothers calls for a differentiated approach in support and intervention strategies.

Table 1: Demographic and socio-economic characteristics of parents

Category	Details / Percentage (%)
Average age of parents	Mother: 46.58 years (± 7.5), Father: 37.25 years (± 7.71)
Age distribution of parents	25-35 years: 37%, 36-45 years: 35%, >45 years: 28%.
Consanguinity	Yes: 33%, No: 67%.
Number of children	1: 6%, 2 or 3: 62%, 4: 32%.
Disease knowledge	Yes: 90%, No: 10%.
Marital status	Married: 70%, Divorced: 20%, Other: 10%.
Schooling	Yes: 45%, No: 55%.
Professional status	Civil servant: 23%, No: 77%.
Couple's monthly income	<3000 DH: 51.67%, 3000 - 6000 DH: 38.33%, >6000 DH: 10%.
Habitat	Urban: 72%, Semi-urban: 22%, Rural: 6%.
Medical Coverage	AMO: 67%, CNSS: 13%, CNOPS: 8%, Others: 2%, None: 10%.

Table 2: Demographic and clinical characteristics of the children studied

Category	Description
Child's gender	Boys: 50%, Girls: 50%.
Average age of children	9.67 years (± 2.54)
Breakdown by age group	6 years: 6.67%, 7 to 12 years: 71.66%, 13 to 16 years: 21.67%.
School enrolment rates	67%
Position in siblings	Senior: 25%, Junior: 30%, Cadet: 45%.
Nature of the genetic disease	B-Thalassemia: 27%, Sickle cell disease: 30%, Hemophilia: 15%, Trisomy 21: 20%, Specific Indeterminate Disease (SID): 8%.

Table 3: Impact of the child's pathology on the couple and the family.

Measurement	Father (± standard deviation)	Mother (± standard deviation)	P-Value
HAD Anxiety	10,08 ± 2,25	11,12 ± 2,3	< 0,01
HAD Depression	11,00 ± 1,33	11,75 ± 1,8	< 0,01
SF12 PCS	42,03 ± 9,77	55,80 ± 16,64	< 0,01
SF12 MCS	43,10 ± 8,2	40,95 ± 15,95	< 0,01
Emotional Score	3,01 ± 0,4	3,23 ± 0,61	NS
Adaptive Score	3,05 ± 0,55	3,17 ± 0,38	NS
Total score	3,03 ± 0,42	3,15 ± 0,42	NS

Legend : p : father/mother comparison ; NS : not significant ; PCS : SF12 physical component score ; MCS : SF12 mental component score ; ; ES: PAR-Qol emotional component score; AS: PAR-Qol adaptive component score; HAD : hospital anxiety and depression scale.

Table 4: Comparative study of HAD, SF12 and PAR Qol scores according to parents' monthly income.

	<3000 DH	3000 - 6000 DH	>6000 DH	p
Anxiety - Mother (HAD)	12,36	10,89	9,00	0.05
Anxiety - Father (HAD)	10,16	10,60	7,50	0.01
Depression - Mother (HAD)	11,36	10,89	9,00	0.05
Depression - Father (HAD)	10,20	10,00	5,50	0.01
SF 12 PCS - Mother	38,12	46,83	54,83	0.01
SF 12 PCS - Father	41,56	46,79	58,56	0.05
SF 12 MCS - Mother	40,96	44,65	51,93	0.05
SF 12 MCS - Father	41,85	49,92	55,61	0.01
PAR QoL ES - Mother	3,36	3,04	2,83	NS
PAR QoL ES - Father	3,55	3,20	3,10	NS
PAR QoL AS - Parent company	3,48	2,98	2,63	NS
PAR QoL AS - Father	3,88	3,18	3,05	NS

Legend: *p: comparison between the two groups; NS: not significant; PCS: SF12 physical component score; MCS: SF12 mental component score; ES: PAR-Qol emotional component score; AS: PAR-Qol adaptive component score; HAD: hospital anxiety and depression scale.*

Table 5: correlation study between parents' psychological state, family difficulties and quality of life.

Measures		HAD Anxiety		HAD Depression	
		r	p	r	p
BY QoL	**Adaptive Score (AS)**	0,278	<0,01	0,103	<0,01
	Emotional Score (ES)	0,503	<0,05	-0,09	<0,05
SF 12	**PCS**	0,405	<0,05	0,055	<0,05
	MCS	-0,433	<0,05	0,002	<0,05

Legend: r = Pearson Correlation Coefficient, p = Coefficient of Significance. PAR QoL AS = Parental Quality of Life Adaptive Component Score, ES = Emotional Component Score. SF 12 PCS/MCS = Short Form 12 Physical/Mental Component Summary. HAD = Hospital Anxiety and Depression Scale.

3.3 Influence of Financial Status on Parents' Psychological Well-Being

In view of the financial discomfort observed in the majority of the families surveyed, we analyzed the score results according to the parents' salary. Analysis of the data in Table 4 reveals essential information about the correlations between family income and different aspects of parental psychological well-being.

3.3.1 Impact of Income on Anxiety and Depression

There is a clear pattern where parents in the lower income bracket (<3000 DH) show higher anxiety and depression scores, compared to those with higher incomes. This pattern is evident in both mothers and fathers, suggesting that lower incomes exacerbate negative psychological states.

3.3.2 Quality of life and income

Quality of life scores, measured by SF-12 PCS (physical health) and MCS (mental health), also show a significant improvement with increasing income, for both mothers and fathers.

3.3.3 Parental Quality of Life Score (PAR QoL)

Variations in PAR QoL scores as a function of income are less pronounced, indicating that emotional and adaptive support may be less directly related to financial status.

3.3.4 Specific correlations

Mothers' anxiety and depression scores, as well as the family's overall score, are correlated with financial and social difficulties, while children's age and sibling rank show no direct correlation with these factors. Table 4 highlights the importance of considering financial aspects when assessing the psychological well-being of families, particularly mothers, and underlines the need for support tailored to their economic situation.

3.4. Study of the correlation between parents' psychological state, family difficulties and quality of life.

Table 5 explores the correlations between parental psychological state (HAD for anxiety and depression) and quality of life (PAR-QoL and SF-12).

3.4.1 Correlations with PAR-QoL

A moderate correlation exists between anxiety and parental adaptation capacity score (AS) ($r = 0.278$, $p < 0.01$), as well as a positive correlation between anxiety and emotional well-being score (ES) ($r = 0.503$, $p < 0.05$). Depression showed weaker correlations with these components.

3.4.2 Correlations with SF-12

Physical health (PCS) and mental health (MCS) are moderately correlated with anxiety ($r = 0.405$ and $r = -0.433$, respectively), but show weaker or non-significant links with depression. These findings highlight the complex links between parents' psychological state, coping skills and emotional management, and their physical and mental health. Parents' anxiety is influenced by their coping skills and emotional well-being, while their mental health has an inverse relationship with anxiety. These findings suggest the importance of an integrated approach to improving parents' quality of life, taking into account both their psychological state and their physical and emotional well-being. Our study revealed a predominance of mothers (80%) among the participants, a similarity found in most articles on the subject. This finding was confirmed by Blanchon and Allouard in 1998 [33] who noted a greater involvement of mothers in the care of sick children. This trend highlights a potential lack of data on fathers' quality of life, an aspect that deserves particular attention. Regarding socio-economic profile, our results indicate that the majority of parents are between 25 and 45 years of age, with high health coverage and a number of children generally below three, aligning our findings with the factors influencing parental quality of life identified in previous studies. The majority of parents in our sample are married and living together, suggesting that the child's illness does not significantly influence marital status. The presence of consanguinity in 33% of couples, a risk factor for Genetic Diseases [34]. Although 90% of parents have some understanding of their child's illness, our study found no significant correlation between this knowledge and parental quality of life. This may indicate that other factors, such as psychological support and available resources, play a more crucial role. Our results on quality of life, measured by PAR-QOL, show average scores, in agreement with ACHACHERA Asma in 2015 [35] but in contradiction with Vasilopoulou and Nisbet in 2016 [36]. This discrepancy could be explained by differences in the populations studied or the methodologies employed. In terms of psychological state, our findings are similar to those of Elliot and Luker [37]and Villani in 2014 [38] who highlighted the negative impact of chronic illness on family and social life. In addition, Trute and Hiebert-Murphy also noted a strong correlation between financial stress and depression in mothers [39]an

aspect supported by our data. Our study reveals moderate levels of anxiety and depression among parents, concordant with the observations of Lisa Zeltzer in 2008 [40] concerning stress and antidepressant use by mothers. In addition, results for SF12 scores indicate a notable alteration in the physical (PCS) and mental (MCS) components for parents, highlighting the profound impact of managing a sick child on their physical and psychological well-being. These results concur with those of studies conducted by Ben Salah Frih in 2010 [41]who also observed a significant alteration in both components of the SF12, especially in the mental aspect.

4. Conclusions

Our study reveals that the overall quality of life of parents in our sample is significantly affected by their child's genetic disease. We identified that psychological and social support for parents and child plays a crucial role in exerting a positive impact on parents' quality of life. On the other hand, factors such as the burden of care, intra-family conflicts, social isolation, financial constraints, stress and anxiety have a significant negative effect. In addition, our research highlights the importance of considering family dynamics and household functioning in the follow-up of children with Genetic Diseases. It is essential to reduce waiting times for care, to strengthen the relationship between parents and healthcare staff, to ensure the availability of treatment, to provide financial assistance to parents with limited social coverage or reduced income, and above all, to ensure clear and effective communication of medical information. These measures must be part of a multidisciplinary approach to child care, taking into account the specific needs of each family. Furthermore, our findings suggest that psychological and emotional support for parents is fundamental. Encouraging the formation of support groups, where parents can share their experiences, get advice, and find valuable emotional support from other families facing similar situations, could considerably improve their quality of life. Such interventions could ease the burden on parents of supporting and caring for their children on an ongoing basis, reducing their financial difficulties and enabling them to better balance their personal lives and leisure time. In conclusion, this study highlights the complex challenges faced by parents of children with Genetic Diseases, and underscores the need for a holistic approach to their support. Future research perspectives should focus on developing integrated strategies to improve the quality of life of affected families, taking into account the multiple dimensions of their experience. Looking to the future, it is imperative that research continues to explore the various facets of quality of life for parents of children with Genetic Diseases. Further studies are needed to understand the specific mechanisms by which environmental, psychological and social factors influence the quality of life of these parents. In particular, future research could focus on the development and evaluation of multidisciplinary, personalized support programs, aimed at meeting the unique needs of each family. In addition, it would be beneficial to examine the effectiveness of different forms of psychological support, including the impact of group therapy versus individual interventions. Evaluating the effectiveness of financial support policies and home health care services would also be valuable areas of research. Finally, it is crucial to explore ways of improving communication between healthcare professionals and families, focusing on the clarity and relevance of the information transmitted. Developing better communication strategies could not only improve parents' understanding of their child's condition, but also boost their confidence in the care process. By incorporating these perspectives into future research, we could significantly improve the quality of life of parents facing these challenges, while broadening our understanding of the overall impact of Genetic Diseases on families.

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