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ORIGINAL PAPER

Quality of life of healthy children with a chronically ill sibling: the role of clinical factors and importance of psychosocial support programs in pediatric care

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ABSTRACT

Introduction: Chronic illness affects a child's quality of life (QoL) – most studies focus on this issue. The aim of our research was to examine the QoL of healthy children who have a sibling with a chronic condition.
Material and methods: The study included 70 participants aged 12–17 years in the study group. The study had a cross-sectional design and was conducted using a demographic survey and the KIDSCREEN-27 questionnaire. The results were compared with an appropriately matched group of healthy children (78) who have healthy siblings. Additionally, the medical records of the ill child were analyzed to assess selected clinical data and estimate the severity of the condition using a custom-designed scale.
Results: The study found that in comparison to the control group, children with a chronically ill sibling showed a lower QoL score in the aspects of independence and parental relationship, as well as community support and peer relationships. The results indicate that healthy children perceived their sibling's illness as significantly more severe compared to the clinical assessment made by a physician. Strong positive correlations were found between the physician's estimated illness severity, the perceived impact of the illness on the healthy sibling, and the participant's perception of illness severity. Additionally, a significantly higher QoL score was observed in certain variables among participants who took part in the sibling support program run by the Gajusz Foundation.
Conclusions: We demonstrated that a sibling's chronic illness significantly affects the QoL of their brothers and sisters. The findings suggest that providing accurate and age-appropriate information can be helpful in preventing anxiety and the development of misconceptions about the sibling's illness, treatment process, and prognosis. Support programs addressed to healthy siblings of chronically ill children may help mitigate the negative effects of the disease on QoL.

KEY WORDS:

quality of life, healthy siblings, chronic illness, perceived impact of illness.

INTRODUCTION

Chronic disease is defined by the World Health Organization (WHO) as an illness that is non-communicable and tends to be of long duration. This group includes diagnoses that are a result of a combination of genetic, physiological, environmental, and behavioral factors and of varying severity [1]. Chronic illness impacts patients' lives in multiple dimensions [2, 3], which is especially true for the pediatric population, as it is characterized by

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continuous and rapid development and thus especially vulnerable to emotional, cognitive, and social disruptions.

Such a diagnosis impacts not only the life of the patient but also social systems that they are a part of [4]. For families a chronic illness of a child may lead to social isolation [5, 6], increased chances of lower socioeconomic status [7] and poorer health outcomes, as well as cognitive problems [8] and a major perceived impact of the child's illness on their life [9].

Long-lasting disease affects the quality of life (QoL) of healthy, adolescent siblings in various dimensions [2]. It may cause social withdrawal [5, 6], affecting familial and peer relationships. In the literature, the impact on their cognitive development, functioning in a school environment, self-esteem, and coping strategies was observed [10]. Internalization of those complex problems may manifest itself in anxiety, depression, and somatic complaints. On the other hand, externalizing behavior problems, such as oppositional or aggressive demeanor may occur.

One potential intervention to address the diminished QoL experienced by healthy siblings of chronically ill children is through targeted aid programs. The "Siblings" program, an initiative of the Gajusz Foundation, established in 2013, stands out as a long-term intervention specifically designed to support healthy siblings of young patients with chronic conditions. This program offers participants a range of extracurricular activities customized to their individual interests, along with opportunities for recreational excursions. Academic support is also provided, with educators available to assist in cases of school attendance issues or declining grades. A dedicated team of specialists oversees the children's overall well-being. Regular group meetings foster a sense of community and facilitate bonding among children who share similar life experiences [11].

In this study, we aimed to assess the impact of chronic illness of a child on the QoL of their healthy sibling, to evaluate the potential ways to ameliorate its potentially detrimental influence.

MATERIAL AND METHODS

The data was collected from healthy siblings of chronically ill patients of the Cardiovascular Surgery Department, as well as the Department of Pediatrics, Immunology and Nephrology in the Polish Mother's Memorial Hospital – Research Institute. Additionally, guardians of chronically ill children were reached through social media support groups. Also, siblings that are a part of the Gajusz Hospice Foundation support program participated in the study (as part of the study group), thanks to the engagement of its coordinators. The children in the control group were recruited randomly in local schools and among acquaintances.

The data was collected using paper and online forms (created using Office 365 Forms application). Written consent to take part in the study was collected from participants and their legal guardians. Subjects were informed that the information will be analyzed anonymously. Participation in the project was voluntary, and consent could be withdrawn at any moment, without consequences.

The study included 70 healthy adolescents of 12–17 years of age, who have siblings with chronic disease (definition according to the WHO [1]). Within the category of chronic diseases, the study group included disorders of various severity – ranging from dermatological conditions with a relatively minor impact on daily functioning to conditions that significantly disrupt daily life, such as genetic diseases with no known cure and oncological conditions. A clear requirement regarding the duration of the disease was not specified (as in WHO definition [1]). However, no participants reported a duration of their sibling's symptoms that would be shorter than 3 months. 14 questionnaires were excluded because of incomplete information or non-somatic chronic illness of the sibling.

The study also included an appropriately matched control group that consists of 78 adolescents with a healthy sibling.

The study utilized a questionnaire to collect sociodemographic data. To objectively measure the QoL of children the Polish adaptation of KIDSCREEN-27 form was used [12]. This tool was created by Mazur *et al.* [12] based on the KIDSCREEN Questionnaires to assess the three main aspects of the QoL – psychological, physical, and social in children aged 8–18 years old. It includes 27 questions, divided into 5 main categories that examine the following dimensions of QoL:

- physical health (5 questions),
- mental well-being (7 questions),
- independence and parental relationship (7 questions),
- community support and peer relationships (4 questions),
- school environment (4 questions).

The questionnaire includes both a self-report version for children and adolescents aged 8–18 years and a proxy version in which a parent or caregiver responds on behalf of the subject. In this study, only the self-assessment type was utilized.

The questionnaire requires respondents to focus on experiences and feelings from the past week. In each question, the subject picks one of five answers, which are subsequently calculated as points (0–4). Results can be standardized to be presented on a 0–100 scale [12].

In the first phase of the statistical comparison, the χ^2 test was used to accept the two groups as equinumerous ($\chi^2(1) = 0{,}43$; $p = 0.511$). The sample data distribution of overall QoL and its dimensions in both groups is close to normal (tested with the Shapiro-Wilk test), thus the *t*-Student test for independent samples was used. To assess correlations between ages of the partici-

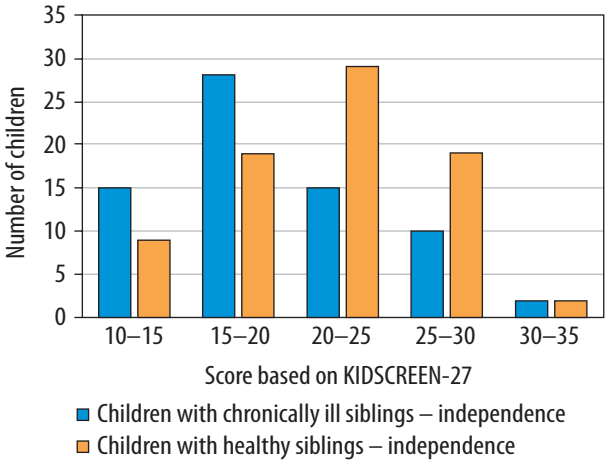

FIGURE 1. Independence and parental relationship

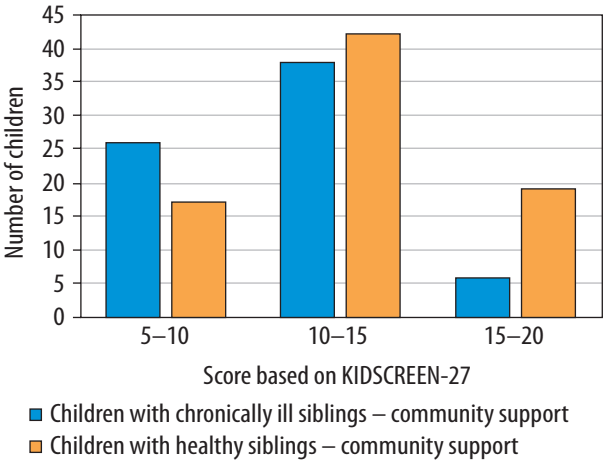

FIGURE 2. Community support and peer relationships

pants with chronically ill siblings and their quality-of-life scores, the r Pearson correlation analysis was performed. The same process was carried out to examine the relationship between the age of an ill sibling and the QoL score of participants. Evaluation of the correlation between the duration of sibling's illness and QoL scores of their brothers and sisters was performed using nonparametric Spearman's rank correlation (rho), as this variable did not meet the assumptions of normal distribution (in Shapiro-Wilk test: $w = 0.669$, $p < 0.001$).

Secondly, an analysis of additional parameters was performed in the group with chronically ill siblings where the following variables were evaluated: (1) estimated severity of the disease assessed by a physician specialized in pediatrics; (2) estimated severity of the disease assessed by siblings, who participated in the study; and (3) estimated impact of the disease on a healthy sibling's QoL – as perceived by subjects themselves.

The first two parameters were ranked on a custom scale from 1–5, where:

1. Mild – an illness with a minor impact on patients' functioning; no persistent medical supervision is required;
2. Manageable – moderate impact on daily life; symptoms can be managed at home;
3. Moderate – a condition that requires treatment and medical supervision, often ongoing with periods of remission and exacerbation;
4. Severe – an illness that profoundly limits patients' daily activities, requires specialized medical care or surgical intervention;
5. Very severe – a potentially life-threatening disease that requires intensive treatment, is physically and emotionally taxing and leads to multiple hospitalizations.

The third variable (self-perceived impact of siblings' illness on participants' QoL) was assessed by subjects of the study on a scale from 0 to 4, assuming that 0 – no impact, 1 – some impact, 2 – medium impact, 3 – large impact, and 4 – huge impact.

The Wilcoxon signed-rank test was utilized for the purpose of comparison between the severity of an illness evaluated by the physician and siblings taking part in the study. In order to examine the correlation between the perceived severity of the disease as assessed by the participant, the estimated severity of the disease assessed by the physician, the perceived impact of the disease on the QoL of healthy siblings, and overall QoL, Spearman's rho correlation analysis was used.

RESULTS

In the first phase, based on the self-report, compared to the control group ($n = 70$) children with chronically ill siblings ($n = 78$) scored lower on the assessment of their independence and parental relationship ($p = 0.014$) (Figure 1), as well as community support and peer relationships ($p = 0.006$) (Figure 2). The effect size was small to medium ($d = -0.41$ and $d = -0.46$ respectively) (Table 1).

No significant differences were found between the groups in overall QoL, as well as the following variables: physical health, mental well-being, and school environment. No statistically significant correlations were found between the QoL (and its components) and the age of participants, as well as the duration of siblings' illness.

A positive, weak correlation ($r = 0.254$, $p = 0.034$) was proven between the age of an ill sibling and subject's QoL score in one of its dimensions (independence and parental relationship).

Additionally, it has been demonstrated that adolescents, who participated in a support group directed to siblings of chronically ill children scored higher in the following QoL variables: community support and peer relationships ($Z = -3.025$; $p = 0.002$; $\eta 2 = 0.062$) as well as school environment ($Z = -1.974$; $p = 0.048$; $\eta 2 = 0.027$). The differences in other variables and overall QoL were statistically insignificant (Table 2).

It was proven that children with a chronically ill sibling assessed the disease as significantly more severe, in comparison to an evaluation performed by a pediatrician ($Z = -5.25$; $p < 0.001$), with medium effect size of $r = 0.63$ (Figure 3). Simultaneously, a strong, positive cor-

TABLE 1. Analysis of differences between children who have a sibling with a chronic illness and children who have a healthy sibling in terms of quality of life and its dimensions

Parameters	Children with chronically ill siblings		Children with healthy siblings		*t*-Student test parameters		
	M	SD	M	SD	*t*	*p*-value	Cohen's d
Physical health	16.09	3.25	16.47	3.96	–0.65	0.518	–
Mental well-being	23.19	3.98	23.59	4.45	–0.58	0.563	–
Independence and parental relationship	19.77	5.62	21.96	5.09	–2.49	0.014	–0.41
Community support and peer relationships	11.51	2.96	13.00	3.47	-2.79	0.006	–0.46
School environment	11.86	3.51	11.32	3.55	0.92	0.357	–
Overall quality of life score	82.41	15.98	86.35	16.76	–1.46	0.147	–

Cohen's d – effect size, M – mean, p –significance level, SD – standard deviation, t – t-statistic from t-Student test for independent samples

TABLE 2. Analysis of differences in quality of life scores between children with a chronically ill sibling who participate in a dedicated support program and those who do not

Parameters	Participants who are involved in a support program		Participants who are not involved in a support program		Mann-Whitney *U* test		
	M	SD	M	SD	Z	*p*-value	η2
Physical health	16.44	3.22	15.96	3.28	–0.331	0.740	0.001
Mental well-being	23.22	4.82	23.17	3.70	–0.155	0.877	<0.001
Independence and parental relationship	21.11	6.40	19.31	5.32	–1.004	0.315	0.007
Community support and peer relationships	13.56	3.35	10.81	2.47	–3.025	0.002	0.062
School environment	13.22	4.12	11.38	3.18	–1.974	0.048	0.027
Overall quality of life	87.56	18.19	80.63	14.92	–1.250	0.211	0.011

η2 – eta squared, representing the effect size, M – mean, p – probability value, SD – standard deviation, z – standardized test statistic from Mann-Whitney U test

relation was found between the evaluation of the illness' subjective severity performed by the participants and the physician ($\rho = 0.770$; $p < 0.001$).

Additionally, a positive correlation was observed between the perceived severity of the illness – whether by the sibling or by the pediatrician – and the degree of its self-reported impact on the sibling's QoL ($\rho = 0.679$; $p < 0.001$; $\rho = 0.609$; $p < 0.001$, respectively). No correlation between those variables and the overall QoL score was found (Table 3).

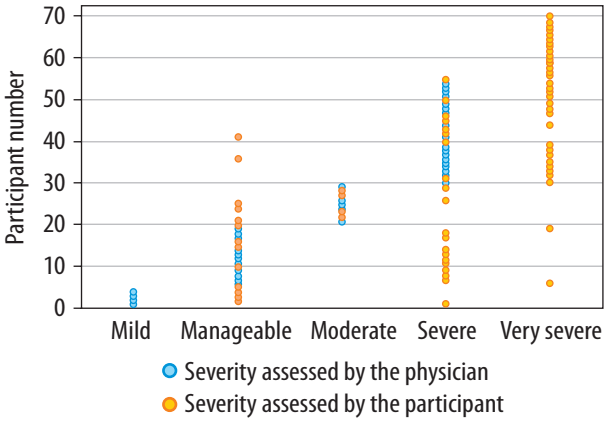

FIGURE 3. Perceived severity of an illness

DISCUSSION

Our study demonstrates that chronic illness in a child impacts the QoL of their healthy siblings in the domains of independence, parental relationships, and peer relationships. These results are consistent with previous research highlighting the psychosocial burden experienced by siblings of chronically ill children [13–15]. Overall QoL did not differ significantly between the two groups, a pattern likewise documented by other authors [16, 17].

It is important to note that not only major experiences, but also daily challenges can influence the psychological well-being of healthy siblings, functioning as significant stressors, as described by Kazak *et al.* [18]. In families dealing with chronic illness, the everyday focus on the ill child may affect the healthy sibling, contributing to feelings of neglect and emotional isolation [19].

Additionally, our study revealed a discrepancy in how children and pediatricians assess the severity of chronic illness. Healthy siblings tended to perceive their brother's or sister's condition as more severe than the clinical

TABLE 3. Analysis of the correlation between perceived severity of an illness assessed by participants, estimated by a physician, self-perceived impact of illness on the healthy sibling's quality of life and the overall quality of life score ($N = 70$)

Parameters		Severity of illness – physician	Severity of illness – participant	Perceived impact of the illness on QoL – participant	Overall QoL score
Severity of illness – physician	*r*	–	0.770	0.609	0.070
	p	–	< 0.001	< 0.001	0.563
Severity of illness – participant	*r*	0.770	–	0.679	0.110
	p	< 0.001	–	< 0.001	0.365
Perceived impact of the illness on QoL – participant	*r*	0.609	0.679	–	70
	p	< 0.001	< 0.001	–	1.000
Overall QoL score	*r*	0.070	0.110	–0.120	–
	p	0.563	0.365	0.324	–

p – significance level, QoL – quality of life, r – Spearman's rank correlation coefficient

assessment indicated. While this difference may reflect the subjective nature of the sibling experience and their immersion in the family's day-to-day reality, it also highlights the potential value of psychoeducation. By involving all family members in the therapeutic process and providing clear, age-appropriate information about the illness, healthcare professionals can help reduce uncertainty, correct potential misconceptions, and foster greater understanding and resilience among siblings [20, 21].

A correlation between the perceived severity of the illness – whether by the sibling or by the pediatrician – and the degree of its reported impact on the sibling's QoL was observed. This suggests that both subjective and objective severity contribute to psychosocial strain. Thus, reducing the perceived burden through improved communication and education may be a way to partly mitigate the impact of chronic illness on healthy siblings.

Notably, our study provides additional insight into how support programs have a positive impact on QoL, especially considering its social dimension, which may seemingly mitigate some of the previously mentioned negative effects.

Participation in a structured support program that combines psychological counseling with recreational and social activities was associated with improved outcomes, particularly in peer relationships and perceived parental attention. Similar conclusions were reached by Besier *et al.* [22], where introduction of an inpatient rehabilitation program for healthy siblings was found to help with emotional and behavioral problems. Supportive programs offering dedicated time, attention, and enjoyable experiences for those adolescents appear to be helpful in supporting higher self-assessed QoL scores. Several of these interventions have demonstrated substantial effectiveness in enhancing self-esteem and improving mood among healthy siblings – for example, the one described by Williams *et al.* [23]. These findings emphasize the importance of interventions, whether inpatient or outpatient, which address not only the clinical needs of children facing chronic conditions, but also the emotional and developmental needs of their siblings.

LIMITATIONS

The study was not free from limitations. Firstly, the research relied solely on the self-assessment of the participants, without incorporating parental evaluations of the children's QoL. Inclusion of parental perspectives could have expanded the data and allowed for a comparison between the evaluation done by subjects of the study and their guardians. Other authors reported differences between parent- and child-reported QoL of healthy siblings [14, 24], which may suggest that adolescents tend not to disclose the full impact of their sibling's illness.

Secondly, the nature of this study required numerous assessments that are inherently subjective. The pediatrician's evaluation of the illness severity was backed by vast knowledge of literature, as well as clinical experience. However, to increase the accuracy of the assessment, a detailed analysis of individual factors such as symptom severity, progression, or the frequency and duration of hospitalizations and medical interventions could be introduced. Those factors may differ greatly from patient to patient; thus, the same diagnosis may present some variation in an evaluation of severity.

Additionally, the group of participants that took part in the support program was relatively small and drawn from a selected population. This initiative, created by the Gajusz Foundation, includes siblings of children receiving hospice care, representing a unique sample that potentially may not represent the broader population of adolescents, whose siblings suffer from a chronic condition but do not require hospice care.

Further research is needed to assess long-term outcomes for siblings of chronically ill children in terms of their QoL. Investigating differences across age groups, illness types,

and cultural factors may be beneficial, especially in the context of introducing a support program, allowing health care teams to tailor interventions more precisely. The inclusion of additional information about potential stressors in the child's school or home environment, such as divorce or death in the family may broaden the context for the analyzed data. Further research may also take into consideration parental personal resources, for example the ability to regulate stress and ways of processing difficult emotions, which may also alter subjects' QoL assessment.

CONCLUSIONS

These findings lead to several clinical and practical implications. The inclusion of interventions focused on healthy siblings in pediatric care, particularly for families dealing with chronic illness, might be beneficial. Additionally, the need for comprehensive family education programs that actively include siblings in discussions about their brother's or sister's illness, treatment, and coping strategies is emphasized. Finally, a conclusion that stands out is a demand for a systemic approach in pediatric practice – one that considers the patient as a part of a family unit with its reciprocal influences.

DISCLOSURES

1. Institutional review board statement: This study was approved by the Ethics Committee of the Scientific Research at the University of Łódź (approval decision no. 3/KEBN-/III/2024-25, dated: 08.04.2025).
2. Assistance with the article: Participation of the Gajusz Hospice Foundation support program.
3. Financial support and sponsorship: None.
4. Conflicts of interest: None.

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