The Journal of Neurological and Neurosurgical Nursing

Pielęgniarstwo Neurologiczne i Neurochirurgiczne

DOI: 10.15225/PNN.2024.13.3.2

JNNN 2024;13(3):100-105

Wydawnictwo Państwowej Akademii Nauk Stosowanych we Włocławku ul. Mechaników 3, pok. 20 87-800 Włocławek

elSSN 2299-0321 ISSN 2084-8021 https://apcz.umk.pl/PNIN

Original

The Quality of Life among Patients with Lyme Disease — a Cross Sectional Study

Jakość życia pacjentów z boreliozą — badanie przekrojowe

Daria Jucha¹, Ewelina Kolarczyk², Joanna Żółtańska³, Bogusława Banaszak-Żak², Agnieszka Młynarska²

Specialist Hospital in Chorzów, Poland

Department of Propaedeutics of Nursing, Faculty of Health Sciences in Katowice, Medical University of Silesia in Katowice, Poland

Collegium Witelona, Legnica State University, Poland

Abstract

Introduction. Quality of life plays an important role in the fields of health and medicine.

Aim. The purpose of this study was to assess the quality of life of Lyme disease patients in relation to sociodemographic factors and life satisfaction.

Material and Methods. The study was conducted by a diagnostic survey among 126 Lyme disease patients. The study used The World Health Organization Quality of Life Questionnaire and the Satisfaction with Life Scale.

Results. Among the respondents, those over 55 years of age had significantly lower somatic quality of life than those younger than 35 years of age (p=0.016). Those with secondary or higher education were characterized by higher quality of life in the somatic sphere than those with vocational education (p<0.05). Women were characterized by a statistically significantly higher quality of life in the social sphere than men(p=0.003). Those in a relationship were characterized by a higher quality of life in the environmental sphere than those who were single (p<0.05), a positive correlation between life satisfaction and quality of life in the somatic and social spheres(p<0.05; rho≤0.5), and in the environmental sphere(p<0.05; rho≤0.7).

Conclusions. Lyme disease patients have an average level of quality of life, the spheres of which are influenced by such factors as gender, age, marital status education and life satisfaction. (JNNN 2024;13(3):100–105) **Key Words:** life satisfaction, Lyme disease, quality of life

Streszczenie

Wstęp. Jakość życia odgrywa istotną rolę w dziedzinie zdrowia i medycyny.

Cel. Celem pracy była ocena jakości życia pacjentów chorujących na boreliozę w odniesieniu do czynników socjodemograficznych oraz do poziomu satysfakcji z życia.

Materiał i metody. Badanie przeprowadzono metodą sondażu diagnostycznego wśród 126. pacjentów chorych na boreliozę. W badaniu wykorzystano kwestionariusz jakości życia The World Health Organization Quality of Life oraz Skalę Satysfakcji z Życia.

Wyniki. Wśród ankietowanych osoby powyżej 55. roku życia charakteryzowały się istotnie niższą jakością życia w sferze somatycznej niż osoby młodsze do 35. roku życia (p=0,016). Osoby z wykształceniem średnim lub wyższym charakteryzowały się wyższą jakością życia w sferze somatycznej, niż osoby z wykształceniem zawodowym (p<0,05). Kobiety charakteryzowały się istotnie statystycznie wyższą od mężczyzn jakością życia w sferze socjalnej (p=0,003). Osoby będące w związku charakteryzowały się wyższą jakością życia z jakością życia w sferze środowiskowej, niż osoby w stanie wolnym (p<0,05), dodatnią korelację pomiędzy satysfakcją z życia a jakością życia w sferze somatycznej oraz socjalnej (p<0,05; rho \leq 0,5), oraz w sferze środowiskowej (p<0,05; rho \leq 0,7).

Wnioski. Chorzy na boreliozę charakteryzują się średnim poziomem jakości życia, na którego sfery wpływ mają takie czynniki jak płeć, wiek, stan cywilny wykształcenie oraz satysfakcja z życia. (PNN 2024;13(3):100–105) Słowa kluczowe: satysfakcja z życia, borelioza, jakość życia

Introduction

Lyme disease, known as Lyme disease, is a multiorgan disease caused by Borrelia spirochetes, mainly transmitted by ticks. It can lead to a wide range of symptoms, including flu-like symptoms [1], and symptoms of late, untreated disease, which can occur weeks to months after initial infection, mainly involve the joints and nervous system [2-4] and can be more difficult to treat. Radiculitis of the spinal nerves, paresthesia's, or facial nerve paresis occur in approximately 75% of cases [5]. According to a study by Rebman et al., patients who have undergone antibiotic treatment for Lyme disease are accompanied by high levels of fatigue, musculoskeletal pain, depression and sleep disturbances [6]. Lyme disease was first described in the United States in 1975 and the bacterial pathogen Borrelia burgdorferi was first identified in 1982 [1,7]. In Poland, the first case of Lyme disease was reported in 1987, and since 1996 Lyme disease has been compulsorily reported and registered. In the first year of the register, 751 cases were reported, and the number of reported cases has been increasing since then. In 2012, the number of cases was 8786 where the incidence was 22.8. In 2017 it was saw the apogee of the incidence, characterized by both the highest number of cases and the highest incidence, at 21514 and 56.0 respectively. In 2022, the number of affected persons was 17338 where the incidence was 45.43 [8,9]. The spread of the disease is thought to be related to a warming climate affecting the biology of ticks, the main transmitters of Lyme disease. Rising temperatures shorten the winter period, prolong tick activity and increase the risk of Lyme disease infection. Climate warming is an important factor influencing the epidemiology of Lyme disease in Poland [10]. The analysis of the risk of contracting Lyme disease in Poland focuses on occupational groups that are particularly vulnerable to infection. Forestry workers, farmers, and people employed in horticulture are high-risk groups due to frequent exposure to ticks in their working environment [11]. With the inclusion of climate change and animal migration, understanding the risk of Lyme disease becomes crucial for effective prevention and health protection of workers in different occupational sectors [12]. Patients' quality of life is one of the key concepts in modern medicine that characterizes the role of physical and psychological functioning during the disease [13]. Research by Rebman et al. shows that posttreatment Lyme disease syndrome (PTLDS) can be successfully identified not only by clinical, physical and laboratory

tests, but also with the support of standardized quality of life questionnaires. The prevalence of Lyme disease is on an upward trend resulting in a greater need for medical care for this group of patients along with effective identification and integrated care of patients with Lyme disease [6]. Therefore, understanding the quality of life of Lyme disease patients is crucial for health care professionals, researchers, and policy makers in developing the effectiveness of medical interventions and preventive systems.

The aim of this study was to assess the quality of life of Lyme disease patients in relation to sociodemographic factors and feelings of life satisfaction.

Material and Methods

The study group consisted of 126 patients (61 males and 65 females) hospitalized from August 2022 to March 2023 at the Department of Infectious Diseases and Hepatology in Bytom, Silesia, Poland. Sociodemographic and clinical characteristics of the study group are included in Table 1. The study was conducted anonymously and voluntarily. All patients were informed about the purpose of the study. The criteria for inclusion in the study were the patient's informed consent to participate in the study, the absence of mental illness and dementia, the absence of cancer, and being of legal age. The study was approved by the Bioethics Committee of the Silesian Medical University in Katowice (no. PCN/CBN/KB/245/22). The study was conducted using a diagnostic survey method with the standardized quality of life questionnaire "The World Health Organization Quality of Life (WHOQoL) — BREF" [14] and the Satisfaction with Life Scale (SWLS) by Ed Diener, Robert A. Emmons, Randy J. Larsen and Sharon Griffin adapted by Z. Juczyński [15]. Sociodemographic data were obtained by means of a self-designed questionnaire. The statistical analysis was performed using PSPP software in the statistical environment of R ver. 3.6.0 and MS Office 2019. Parametric tests (Student's T test or ANOVA analysis of variance) or their non-parametric equivalents (Mann-Whitney U test or Kruskal-Wallis test) were used to analyse the quantitative variables presented by groups. Verification of the presence of a relationship between variables was performed using Spearman rank correlation analysis. The significance level was taken as p=0.05.

 Table 1. Sociodemographic and clinical characteristics of the study group

Variable	Frequency	%
1	2	3
Age		
Up to 35 years	35	27.8
36–55 years	56	44.4
Over 55 years	35	27.8
Gender		
Women	51.6	
Men	61	48.4
Marital status		
Single	30	23.8
Married	66	52.4
Widow/Widower	17	13.5
Divorced	13	10.3
Education		
Primary	4	3.2
Vocational	30	23.8
Secondary	40	31.7
Higher	52	41.3
Place of residence		
Village	17	13.5
City up to 100,000 inhabitants	73	57.9
City over 100,000 inhabitants	36	28.6
Co-existing diseases		
Yes	41	32.5
No	85	67.5
Time from Lyme disease diagnosis		
<1 month	14	11.1
2–6 months	31	24.6
6–12 months	25	19.9
>12 months	56	44.4
Time of stay in the hospital		
≤1 week	49	38.9
≤2 weeks	55	43.7
≤3 weeks	13	10.3
≥3 weeks	9	7.1
Rehospitalizations due to Lyme disease		
Yes	59	46.8
No	67	53.2
Rehospitalization period (year range)*		
2014–2016	3	3.9
2017–2019	12	15.8
2020–2022	17	22.4
The current hospitalization is the	h	57.0
nrst one	44	37.9

Table 1. Continued

1	2	3
Amount of rehospitalization*		
1	40	54.1
2	20	27.0
≥3	14	18.9
Number of tick bites in a lifetime		
1–2 bites	90	71.4
3–4 bites	22	17.5
≥4 bites	14	11.1
Erythema on the skin after a bite		
Occurred	57	45.2
Didn't occurred	29	23.0
Didn't remember	40	31.8
*The questions do not apply to all patients		

"The questions do not apply to all patients

Results

Analysis of the results showed that the QOL of the survey group was at an average level. In the psychological sphere, the average was M=55.19 where Max=75.00 and Min=38.00. The somatic sphere showed M=48.53 where Max=88.00 and Min=13.00. The social sphere showed M=49.09 with Max=94.00 and Min=15.00; and the environmental sphere showed M=50.99 with Max=81.00 and Min=6.30. The QOL level is shown in Table 2.

Table 2. Quality of life for Lyme disease patients (N=126)

Quality of life assessment	Frequency	%
1	2	3
Quality of life in the somatic sphere		
Low	38	30.2
Average	57	45.2
High	31	24.6
Quality of life in the psychological sphere		
Low	40	31.7
Average	50	39.7
High	36	28.6
Quality of life in the social sphere		
Low	29	23.0
Average	72	57.1
High	25	19.8

Table 2. Continued			
1	2	3	
Quality of life in the environmental sphere			
Low	42	33.3	
Average	50	39.7	
High	34	27.0	
Quality of life overall			
Low	34	27.0	
Average	54	42.9	
High	38	30.2	

.

In somatic sphere woman had a slightly higher QOL than men (p=0.454). Results of one-way ANOVA and Kruskal–Wallis test of variance significant statistical differences (p<0.05) across age groups of respondents. There were also significant statistical differences (p<0.05) between those with vocational education and those with secondary and tertiary education. Those with vocational education had statistically significantly lower QOL in the somatic sphere than those with secondary education (p=0.022) or higher education (p=0.019).

In terms of quality of life in the psychological sphere, the analysis showed no statistically significant differences according to the gender, age, marital status and education of the respondents (p>0.05).

The results of the T-test and the Mann–Whitney U test for independent samples showed that women had a statistically significantly higher social QOL than men (p=0.003). Age, marital status and education did not affect the level of QOL in the social sphere (p>0.05). It was shown that those with vocational education had a slightly lower QOL in the social sphere than the others, but these differences were statistically insignificant (p=0.005).

The study showed that those in a relationship had a statistically significant (p<0.05) higher QOL in the environmental domain than those participants who were single. Other sociodemographic factors did not significantly affect patients' QOL in the environmental sphere (p>0.05).

Life satisfaction was low in half of the respondents (67; 53.20%) and high in only eight respondents (8.70%). Statistical analysis using the Shapiro–Wilk test

showed a statistically significant positive correlation between life satisfaction and QOL in the somatic and social spheres (p<0.05; rho≤0.5), as well as in the environmental sphere (p<0.05; rho≤0.7). However, there was no statistically significant correlation (p>0.05) between life satisfaction and QOL in the psychological sphere. This means that the higher the life satisfaction was, the higher the QOL in those in the somatic, social, and environmental spheres. The data are presented in Table 3.

Discussion

Patients' quality of life is one of the key concepts in modern medicine that characterizes the role of physical and psychological functioning during the disease. The present study examined the average level of quality of life among patients with Lyme disease and the impact of significant individual sociodemographic factors and life satisfaction on the somatic, social, and environmental domains. According to Hill, the quality of life of patients with chronic Lyme disease is related to patients' own perceptions of the disease and coping, and of the disease perceptions, consequences and identity dimensions are most strongly related to quality of life. In his study, Hill showed that behavioral withdrawal and substance use were the coping strategies most strongly associated with emotional health outcomes [16]. The present study found a mean QOL in the psychological domain, which, as hypothesized by the WHOQoL BREF questionnaire, also refers to feelings, both positive and negative, that may contribute to illness-related emotions. According to Malysh et al., patients with Lyme disease show a significant decline in physical, social, and emotional health indicators compared to healthy individuals. The deterioration of QOL indices generally depends on the clinical characteristics of the disease, the duration of the disease, the presence of Lyme arthritis, neuroborreliosis, cognitive impairment, multiorgan involvement and the stage of the disease [17]. This is consistent with the results of the present study where quality of life in both somatic, psychological, social, and environmental domains was average. A long-term observational study by Wills et al. among US patients with Lyme disease showed QOL was below the US population average in both the somatic and mental domains, and increased to slightly above the

Table 3. Impact of life satisfaction on the quality of life of Lyme disease patients

		Somatic sphere	Psychological sphere	Social sphere	Environmental sphere
Satisfaction from life	rho	0.446	0.128	0.396	0.518
	р	< 0.001	0.153	< 0.001	< 0.001

rho — Spearman's rank correlation coefficient; p — level of statistical significance

national average after 3 years of follow-up both. Baseline QOL scores were lowest in those with late-stage disease (p<0.01), but also increased to national averages by the end of follow-up. In multivariate analysis, the only factors significantly associated with long-term symptoms or lower QOL scores were other comorbidities unrelated to Lyme disease [18]. The present study was also observational but was a cross-sectional study in which more than half of the respondents (85; 67.50%) had no comorbidities and QOL was average. During Borrelia burgdorferi infection, which causes Lyme disease, a wide spectrum of disorders of the peripheral and central nervous system is observed. Approx. 10-25% of patients with neuroborreliosis are characterized by non-specific symptoms of both the somatic and psychological spheres, which consequently significantly impede the patients' daily functioning. Staszewska, in her study, demonstrated poor mental health in people diagnosed with neuroborreliosis, who experience difficulties in functioning in social, occupational, and educational areas. According to Staszewska, it becomes crucial to deepen research that considers mental health in tickborne diseases, including neuroborreliosis, and to adapt and implement appropriate preventive and therapeutic interventions [19]. The present study on the quality of life of patients with Lyme disease also included the psychological sphere, the results of the present study showed that sociodemographic factors such as gender, age, marital status, education, and place of residence did not affect the psychological sphere of QOL. Also, life satisfaction did not influence QOL, which, according to the results obtained, may be due to the low level of life satisfaction of patients with Lyme disease. It is possible that the psychological sphere of QOL is related to the severity of the disease, a relationship demonstrated by the study of Yuskevych et al. The authors of the cited study showed that patients with Lyme disease progressing to arthritis not only had significantly reduced motor activity, but also psychological adaptation to their disease [20]. The occurrence of high pain intensity compared to the control group in the cited studies may be responsible for this condition, which may result in reduced psychological well-being. Yuskevch's team, using the SP-36 questionnaire, showed low QOL scores in patients with Lyme disease in all its components: mental health, vitality, emotional role, social activity and physical functioning. This is consistent with the results of the present study in which QOL was low in 27% and average in 42.9% of respondents. In the study by Yuskevch et al., it was found that patients' QOL was influenced by the duration and activity of the disease, while age was not a significant factor affecting QOL. Similarly, the present study found no correlation between age and overall QOL score, with only a significant effect of age impacting on the somatic domain, where better quality

of life occurred in younger individuals. In contrast, the present study did not include the effect of duration and activity of Lyme disease on QOL but included nearly half of the patients with a time since diagnosis of at least one year (56; 40.40%) and who were hospitalized for Lyme disease (59; 46.80%). Research on the QOL of patients with Lyme disease is important for improving the healthcare of patients with this condition. The results of QOL surveys of patients with Lyme disease will allow medical staff and family members caring for patients to identify the primary health care needs of this patient group.

Conclusions

Lyme disease patients have an average level of quality of life, the spheres of which are influenced by factors such as gender, age, marital status education, and life satisfaction. Psychological quality of life is not dependent on socio-demographic factors and life satisfaction, so in the care of Lyme disease patients, the demonstration of psychological support by medical staff plays an important role in medical care.

Implications for Nursing Practice

This study addresses the QOL of Lyme disease patients in relation to sociodemographic factors as well as life satisfaction. A holistic approach to nursing care involves considering patients' QOL in evidence-based nursing practice. Making the right therapeutic, diagnostic, nursing or educational decisions, which fall within the nurses' remit, requires the nurse to properly recognize the clinical situation and identify the patient's emotional states, preferences and attitudes. In order to properly prepare the patient for self-care and self-care, the patient's education should take into account the resources of the patient's somatic, social and environmental spheres, to ensure that the therapeutic recommendations are feasible to implement by the patient in everyday life. Recognizing the psychological state in relation to QOL is an important factor in providing appropriate psychological and emotional support and can contribute to better communication with the patient which translates into better quality of nursing care provided.

References

- [1] Schoen R.T. Lyme disease: diagnosis and treatment. *Curr Opin Rheumatol.* 2020;32(3):247–254.
- [2] Steere A.C., Strle F., Wormser G.P. et al. Lyme borreliosis. *Nat Rev Dis Primers*. 2016;2:16090.

- [3] Skar G.L., Simonsen K.A. Lyme Disease. Retrieved February 4, 2024, from https://www.ncbi.nlm.nih.gov/ books/NBK431066/
- [4] Wysocki J. Neurootologiczne postacie boreliozy. *Pol Prz* Otorynolaryngol. 2020;9(4):39–44.
- [5] Rauer S., Kastenbauer S., Hofmann H. et al. Guidelines for diagnosis and treatment in neurology — Lyme neuroborreliosis. *Ger Med Sci.* 2020;18:Doc03.
- [6] Rebman A.W., Bechtold K.T., Yang T. et al. The Clinical, Symptom, and Quality-of-Life Characterization of a Well-Defined Group of Patients with Posttreatment Lyme Disease Syndrome. *Front Med (Lausanne)*. 2017;4:224.
- [7] Burgdorfer W., Barbour A.G., Hayes S.F., Benach J.L., Grunwaldt E., Davis J.P. Lyme disease-a tick-borne spirochetosis? *Science*. 1982;216(4552):1317–1319.
- [8] Wojewódzka Stacja Sanitarno-Epidemiologiczna w Poznaniu. *Borelioza z Lyme*. Retrieved December 30, 2023, from https://www.gov.pl/web/wsse-poznan/ borelioza-z-lyme
- [9] Kmieciak W., Ciszewski M., Szewczyk E.M., Siński E., Welc-Faleciak R. Borelioza i kleszczowe zapalenie mózgu — epidemiologia w Polsce w latach 2016–2020. Aktualne Problemy badawcze. Retrieved October 21, 2022, from https://www.pzh.gov.pl/wp-contentuploads2021/03Kl eszczoweZapalenieMozgu-raport-PZH_2021.pdf
- [10] Lang A. W Polsce rośnie liczba chorych na boreliozę i inne choroby odkleszczowe. Retrieved October 21, 2022, from https://www.termedia.pl/lekarzspecjalista/W-Polsce -rosnie-liczba-chorych-na-borelioze-i-inne-chorobyodkleszczowe,33404.html
- [11] Tokarska-Rodak M., Plewik D., Kozioł-Montewka M., Szepeluk A., Paszkiewicz J. Ryzyko zakażeń zawodowych *Borrelia burgdorferi* u pracowników leśnictwa i rolników. *Med Pr.* 2014;65(1):109–117.
- [12] Mazur P., Nowak G. Zachorowalność na boreliozę w wybranych zawodach w Polsce. Retrieved January 3, 2024, from https://www.ciop.pl/CIOPPortalWAR/ appmanager/ciop/pl?_nfpb=true&_pageLabel=P5420023 7581597225259567&html_tresc_root_id=1954&html_ tresc_id=1955&html_klucz=8888&html_klucz_spis=
- [13] Haraldstad K., Wahl A., Andenæs R. et al. A systematic review of quality of life research in medicine and health sciences. *Qual Life Res.* 2019;28(10):2641–2650.
- [14] World Health Organization. WHOQoL. Measuring Quality of Life. Retrieved February 23, 2023, from https:// www.who.int/tools/whoqol

- [15] Juczyński Z., Ogińska-Bulik N. Narzędzia pomiaru w promocji i psychologii zdrowia — Skala Satysfakcji z Życia (SWLS). Pracownia Testów Psychologicznych Polskiego Towarzystwa Psychologicznego, Warszawa 2009.
- [16] Hill E.M., Frost A. Illness perceptions, coping, and health-related quality of life among individuals experiencing chronic Lyme disease. *Chronic Illn.* 2022;18(2):426–438.
- [17] Malysh T.Y., Trishchynska M.A., Panasyuk O. Impact of clinical characteristics of Lyme borreliosis on patients' life quality. *Wiad Lek*. 2023;76(9):1943–1948.
- [18] Wills A.B., Spaulding A.B., Adjemian J. et al. Long-term Follow-up of Patients With Lyme Disease: Longitudinal Analysis of Clinical and Quality-of-life Measures. *Clin Infect Dis.* 2016;62(12):1546–1551.
- [19] Staszewska K. The state of mental health in people with a diagnosis of neuroborreliosis. *Med Pr.* 2021;72(3):259– 266.
- [20] Yuskevych V.V., Zhulkevych I.V., Makhovska O.S., Smiyan S.I. Assessment of quality of life in patients with Lyme arthritis and rheumatoid arthritis. *Reumatologia*. 2022;60(1):35–41.

Corresponding Author:

Ewelina Kolarczyk 🕩

Department of Propaedeutics of Nursing, Faculty of Health Sciences in Katowice, Medical University of Silesia in Katowice Francuska 20/24 street, 40-027 Katowice, Poland e-mail: ekolarczyk@sum.edu.pl

Conflict of Interest: None Funding: None Author Contributions: Daria Jucha^{A-F}, Ewelina Kolarczyk^{A,C,E}, Joanna Żółtańska^{E-G}, Bogusława Banaszak-Żak^{G,H} (b, Agnieszka Młynarska^{G-I} (b)

A — Concept and design of research, B — Collection and/or compilation of data, C — Analysis and interpretation of data, D — Statistical analysis, E — Writing an article, F — Search of the literature, G — Critical article analysis, H — Approval of the final version of the article, I — Acquisition of assets [eg financial]

Received: 1.05.2024 Accepted: 27.06.2024