

A Novel Scoring System Approach to Assess Patients with Lyme Disease (Nutech Functional Score)

Geeta Shroff, Petra Hopf-Seidel¹

Director, Nutech Mediworld, New Delhi, India, ¹Neurologist and Psychiatrist, Expert for Lyme Disease, Ansbach, Germany

Abstract

Introduction: A bacterial infection by *Borrelia burgdorferi* referred to as Lyme disease (LD) or borreliosis is transmitted mostly by a bite of the tick *Ixodes scapularis* in the USA and *Ixodes ricinus* in Europe. Various tests are used for the diagnosis of LD, but their results are often unreliable. We compiled a list of clinically visible and patient-reported symptoms that are associated with LD. Based on this list, we developed a novel scoring system. **Methodology:** Nutech functional Score (NFS), which is a 43 point positional (every symptom is subgraded and each alternative gets some points according to its position) and directional (moves in direction bad to good) scoring system that assesses the patient's condition. **Results:** The grades of the scoring system have been converted into numeric values for conducting probability based studies. Each symptom is graded from 1 to 5 that runs in direction BAD → GOOD. **Conclusion:** NFS is a unique tool that can be used universally to assess the condition of patients with LD.

Keywords: *Borrelia burgdorferi*-antibodies, human embryonic stem cells, Lyme disease, Nutech functional score

INTRODUCTION

“Lyme disease” (LD) or “borreliosis” is a bacterial infection caused by the spirochete *Borrelia burgdorferi* (*Bb*) and is transmitted to humans mostly by the bite of a tick (in Europe mostly by *Ixodes ricinus*). In Europe, approximately 5%–25% of the people are found to be positive for *Bb*-antibodies.^[1,2] According to the Centers for Disease Control and Prevention (CDC) in the USA, the number of cases with LD has increased greatly, i.e., from 19,931 in 2006 to >300,000 in 2013.^[3,4]

The course of LD mostly consists of three phases: early localized stage, early disseminated stage, and late disseminated stage.^[5] Initially, after the tick bite or in the early localized stage (within the first 30 days), a person can develop an erythema migrans, a red and expanding rash, which is a typical and sure sign of the infection. Another early and sure but more rare sign of infection is a lymphocytoma, a bluish swelling of the earlobe, the nipple, or on the scrotum. Other general symptoms after an infection with *Bb* include marked fatigue, headache, fever, chills, swollen lymph nodes, and muscle and joint aches.^[5] In the second stage, referred as early disseminated stage, the bacteria can affect the central and peripheral nervous

system, and/or the heart and/or the musculoskeletal and/or the gastrointestinal and/or urogenital system.^[5-7] The third or chronic stage of LD can last from months to years after the infection and shows equal manifestations in young and adults.^[7]

An erythema migrans (the red rash on the skin) is the key indicator of borrelia infection, which is unfortunately only present in 50% of the cases. If left untreated, the infection leads to conditions such as peripheral neuropathy, encephalopathy with impaired cognitive abilities or to migrating mono- or polyarticular arthritis.^[8] Many other signs may occur such as heart block, headache, myalgia, and facial paralysis or paralysis of extremities. Thus, several diagnostic tests are developed to confirm the infection with *Bb*, the reason for LD. Serological testing is done using enzyme-linked immunosorbent assay (ELISA) and Western blots. Tests to exclude other reasons than *Bb* for the observed central nervous impairments are the magnetic resonance imaging (MRI) and the single photon emission computed tomography (SPECT) scan, but

Address for correspondence: Dr. Geeta Shroff, Nutech Mediworld, H-8, Green Park Extension, New Delhi - 110 016, India. E-mail: geetashroff@hotmail.com

This is an open access article distributed under the terms of the Creative Commons Attribution-NonCommercial-ShareAlike 3.0 License, which allows others to remix, tweak, and build upon the work non-commercially, as long as the author is credited and the new creations are licensed under the identical terms.

For reprints contact: reprints@medknow.com

How to cite this article: Shroff G, Hopf-Seidel P. A Novel Scoring System Approach to Assess Patients with Lyme Disease (Nutech Functional Score). J Global Infect Dis 2018;10:3-6.

Access this article online

Quick Response Code:



Website:
www.jgid.org

DOI:
10.4103/jgid.jgid_11_17

the latter is rarely done.^[9,10] Unfortunately, the results of these tests cannot be completely relied on to confirm the presence of LD. Therefore, the CDC recommends that the diagnosis of LD should be based on clinical signs and symptoms, the results of blood tests should only be used as supporting evidence as they may give false results.^[11]

There are scoring systems for several other medical conditions such as spinal cord injury and cerebral palsy that assess the condition of patients based on the symptoms.^[12,13] However, there is no such discrete system to assess the patients with LD. Nutech Mediworld, a center offering human embryonic stem cells for incurable and terminal conditions has developed a novel numeric approach, the Nutech functional score (NFS) to assess the condition of patients with LD based on clinical symptoms. NFS for LD is a 43 point positional (every symptom is subgraded and each alternative gets some points according to its position) and directional (moves in direction bad to good) scoring system that can be used to assess the diagnosis of LD and the effects of any given treatment.

METHODOLOGY

We have been treating patients with LD since the year 2000. The cases with LD admitted at our facility visited directly or were referred by other hospitals/institutions. They were either previously diagnosed with LD or underwent diagnosis at our facility. We evaluated each patient for their presented symptoms, common, or rare and recorded them in the diagnostic history.

Thus, over the years, a list of symptoms was prepared which included all the observed symptoms so far and was used thereafter to stage the patients with LD. This list of symptoms has been revised from time to time to maintain accuracy according to literature studies and our own experiences. Each symptom is evaluated on the basis of five ordinal grades running in BAD → GOOD direction. We used this scoring system to define patients with LD who were previously assessed with various other diagnostic tests including ELISA, Western blot, MRI, and SPECT scan.

RESULTS

We developed a 43-point scoring system that includes many possible presently known symptoms associated with LD. NFS grades for all the assessed symptoms are presented in Appendix 1. NFS for LD has been organized into three groups depending on the kind of symptoms. Group 1 includes symptoms of the central nervous system with neurological and cognitive deficits; Group 2 includes symptoms associated with the muscular and skeletal system, and Group 3 includes all other symptoms such as those associated with the sensory system (vision, hearing), the cardiac and respiratory system, the urogenital and gastrointestinal system. Hormonal changes caused by LD have not been included as they are not clinically visible. The symptoms that are found not to be associated with the infection by *Bb* are scored as not afflicted in the

ailment (NA). If a symptom is not present in the individual patient, then it is graded as not existing.

The five ordinal scores (1, 2, 3, 4, and 5) run in the direction of 1 → 5 i.e., BAD → GOOD. These five scores that lie in a range of (0.5, 5.5) are equidistant to each other and are continuous. The scores have been converted into numeric values to facilitate the conduct of probability based studies which require a range of (-1, 1) or (0, 1). This configuration can be used universally for one symptom. The polynomial smoothing and graphical methods have been used to derive an equation for converting categorical scores into numeric scores. The equation is as follow:

$$Y_n = 0.096 \times (Y_c + 0.5) - 0.166$$

Where Y_n = numeric score and Y_c = categorical score.

Table 1 shows how five/three categorical scores (0.5–5.5) for symptoms that can be converted to five/three numeric scores in the range (0, 1).

DISCUSSION

LD is reported to be a highly misdiagnosed condition. The first factor responsible for misdiagnosis is that the symptoms of LD are similar to a wide range of other medical conditions including chronic fatigue syndrome, fibromyalgia, Alzheimer's disease, Parkinson's disease, multiple sclerosis, and others. Co-infections caused by the tick transmitting *Bb* at the same time contribute to a misdiagnosis too. They make the clinical recognition of the underlying disease more difficult.^[14] Interpretations of serology and other tests for the diagnosis of chronic LD do not give reliable validity. The modern tests include immune fluorescent staining for cell wall deficient forms of *Bb*, lymphocyte transformation tests and polymerase-chain reaction of different tissues and urine.^[15,16] The CDC still recommends the use of a two-tier approach, i.e., ELISA and Western blot, even if it only has a sensitivity of 44% to 56%, if tested 4–6 weeks after infection.^[17] At present, tests for LD in the USA are against only one strain of *Bb*, whereas there are more than 100 strains of *Borrelia* worldwide, of which 9 of them are known to be pathogenic to humans and cause LD-like illnesses. Normal laboratories are unable to isolate and identify these species in daily routine. Only specialized research laboratories can differentiate the different species. This could be one of the reasons why patients can get a false-negative laboratory result, even if they suffer from LD. The other crucial factor is that most of the diagnostic tests are indirect as they look for antibodies to *Bb*, but not for the organism itself. Because antibodies often persist even after the organism is no longer present, the tests will show positive results and lead to the therefore false diagnosis of a still active infection. On the other hand, sometimes no antibodies at all can be found, i.e., if antibiotics or immunosuppressant were given in the early course of the infection. Dark-field microscopy is another but direct method which is used in research and by some doctors treating LD to allow them a direct microscopic

Table 1: Conversion table from categorical scores to numeric range for Nutech functional score

Number of scores	Y _n	Y _c				
		1	2	3	4	5
5	Score (Y _n)	0.122	0.310	0.500	0.690	0.89
	Range (Y _n)	0-0.241	0.241-0.379	0.379-0.621	0.621-0.759	0.759-1.00
3	Score (Y _n)	0.167	0.500	0.833	-	-
	Range (Y _n)	0-0.333	0.333-0.667	0.667-1.00	-	-

Y_n: Numeric score, Y_c: Categorical score

approach to the blood with the *Bb* spirochetes. However, until now, there is no 100% safe and valid method for confirming the presence of LD by tests. Therefore, the diagnosis of LD should predominantly be based on the clinical picture as it has been already suggested by the CDC in the USA. Physicians should try to get the history of the patient and his many and often fluctuating symptoms.^[11]

The NFS scoring system developed by our facility seems to be a simple and appropriate method to confirm the diagnosis of patients with LD based solely on clinical symptoms. It has enlisted many of the possible clinical symptoms that are associated with LD. Although symptom-based questionnaires or checklists are available for LD, a numeric scoring system is not yet available. Renowned work in this field is done by Dr. Burrascano Jr., who has given a checklist of symptoms that help in identifying whether these symptoms are associated with LD or other co-infections caused by a tick bite. He has categorized the symptoms of LD as none, mild, moderate, and severe.^[18] The Horowitz Lyme-MSIDS Questionnaire also enlists all those symptoms that we have included in the NFS; however, this questionnaire is not validated statistically.^[19] Although the NFS system is inspired from their work; it is a numeric newly developed system that has been validated statistically.

We illustrate an example on how the NFS-system is used to grade a patient with LD in a differentiated manner in Table 2. The total NFS score is calculated by counting the grades of all the symptoms. Suppose, this female patient scored 20 before treatment and the score increased to 74 after the therapy. This signifies a considerable improvement in her condition. As we can add or subtract grades in NFS, it can help in recognizing even the slightest improvements/deterioration in the condition of the patient. This number of grades can furthermore converted into numeric values to facilitate the conduct of probability based studies.

CONCLUSION

There is a lack of a discrete and exhaustive clinical scoring system for patients with LD until now. The serological testing and other laboratory tests have low specificity and sensitivity. A numeric scoring system like NFS can be a novel tool that can help doctors worldwide to validate and confirm the diagnosis of LD for patients. This scoring system can also be used only in parts according to the clinical condition of the patient,

Table 2: A hypothetical example showing Nutech functional score of a patient before and after therapy

Parameters	NFS	
	Before therapy	After therapy
Numbness	1	4
Tingling	1	3
Burning of skin	NA	NA
Tremors of extremities	1	3
Short-term memory	1	4
Orientation	NA	NA
Depression	1	4
Irritability	1	2
Bowel-sensation	NA	NA
Bowel-control	NA	NA
Bladder-sensation	NA	NA
Bladder-control	NA	NA
Sleep disorder-hypersomnia	NA	NA
Sleep disorder-hyposomnia	NA	NA
Speech	NA	NA
Pain-area	1	4
Pain-intensity and type	1	3
Stiffness of muscles	NA	NA
Paralysis of extremities	NA	NA
Fatigue	1	5
Sitting-balance	NA	NA
Sitting-time	NA	NA
Standing-balance with calliper	NA	NA
Standing-time	1	4
Walking with aid	1	4
Walking distance	NA	NA
Calipers for standing	2	4
Myalgia	1	5
Sensitivity to light	1	3
Vision	1	2
Nystagmus or squint	NA	NA
Hearing	1	2
Tinnitus	NA	NA
Heart-Palpitation	1	5
Allergy to food	1	5
Appetite	1	3
Unintended weight loss	NA	NA
Unintended weight gain	NA	NA
Swallowing	NA	NA
Constipation	NA	NA
Diarrhea	NA	NA

Contd...

Table 2: Contd...

Parameters	NFS	
	Before therapy	After therapy
Hair loss	NA	NA
Other infections	1	5
Total NFS	20	74

NFS: Nutech functional score, NA: Not afflicted

i.e., only describing the changes of the individual symptoms that are present in the patient.

Acknowledgments

The authors acknowledge all the patients, doctors, and staff members of Nutech Mediworld. The authors also acknowledge Knowledge Isotopes Pvt. Ltd.

Financial support and sponsorship

Nil.

Conflicts of interest

There are no conflicts of interest.

REFERENCES

- Biesiada G, Czepiel J, Leśniak MR, Garlicki A, Mach T. Lyme disease: Review. Arch Med Sci 2012;8:978-82.
- Derdáková M, Lencáková D. Association of genetic variability within the *Borrelia burgdorferi* sensu lato with the ecology, epidemiology of Lyme borreliosis in Europe. Ann Agric Environ Med 2005;12:165-72.
- Seibel MM, Smith DM, Levesque L, Borten M, Taymor ML. The temporal relationship between the luteinizing hormone surge and human oocyte maturation. Am J Obstet Gynecol 1982;142:568-72.
- Stanke JJ, Fischer AJ. Embryonic retinal cells and support to mature retinal neurons. Invest Ophthalmol Vis Sci 2010;51:2208-18.
- Steere AC. Lyme disease. N Engl J Med 2001;345:115-25.
- Manzoor K, Aftab W, Choksi S, Khan IA. Lyme carditis: Sequential electrocardiographic changes in response to antibiotic therapy. Int J Cardiol 2009;137:167-71.
- Girschick HJ, Morbach H, Tappe D. Treatment of Lyme borreliosis. Arthritis Res Ther 2009;11:258.
- Bacon RM, Kugeler KJ, Mead PS, Centers for Disease Control and Prevention (CDC). Surveillance for Lyme disease – United States, 1992-2006. MMWR Surveill Summ 2008;57:1-9.
- Seltzer EG, Shapiro ED. Misdiagnosis of Lyme disease: When not to order serologic tests. Pediatr Infect Dis J 1996;15:762-3.
- Wormser GP, Dattwyler RJ, Shapiro ED, Halperin JJ, Steere AC, Klemmner MS, et al. The clinical assessment, treatment, and prevention of Lyme disease, human granulocytic anaplasmosis, and babesiosis: Clinical Practice Guidelines by the Infectious Diseases Society of America. Clin Infect Dis 2006;43:1089-134.
- Spalton DJ. Posterior capsular opacification after cataract surgery. Eye 1999;13:489-92.
- Waring WP 3rd, Biering-Sorensen F, Burns S, Donovan W, Graves D, Jha A, et al. 2009 review and revisions of the international standards for the neurological classification of spinal cord injury. J Spinal Cord Med 2010;33:346-52.
- Palisano R, Rosenbaum P, Walter S, Russell D, Wood E, Galuppi B, et al. Development and reliability of a system to classify gross motor function in children with cerebral palsy. Dev Med Child Neurol 1997;39:214-23.
- Kozeis N. Brain visual impairment in childhood: Mini review. Hippokratia 2010;14:249-51.
- Aguero-Rosenfeld ME, Wang G, Schwartz I, Wormser GP. Diagnosis of Lyme borreliosis. Clin Microbiol Rev 2005;18:484-509.
- Centers for Disease Control and Prevention (CDC). Recommendations for test performance and interpretation from the second national conference on serologic diagnosis of Lyme disease. MMWR Morb Mortal Wkly Rep 1995;44:590-1.
- Stricker RB, Johnson L. Lyme disease: The next decade. Infect Drug Resist 2011;4:1-9.
- Joseph J. Burrascano Jr. Advanced Topics in Lyme Disease. Diagnostic Hints and Treatments Guidelines for Lyme and Other Tick Borne Illnesses; 2008. Available from: <http://www.lymenet.org/Burrguide200810.pdf>. [Last accessed on 2015 Aug 26].
- Mohand-Said S, Hicks D, Simonutti M, Tran-Minh D, Deudon-Combe A, Dreyfus H, et al. Photoreceptor transplants increase host cone survival in the retinal degeneration (rd) mouse. Ophthalmic Res 1997;29:290-7.

Appendix 1: Nutech functional score for Lyme disease

Parameters	Description	Score
Group-1: Neurological and cognitive (areas affected: Lower/upper extremities, back, trunk, head including face)		
Numbness	Not afflicted in LD	NA
	Not existing	NE
	≤3 areas involved	1
	3 areas involved	2
	2 areas involved	3
	1 area involved	4
	Numbness disappeared	5
Tingling	Not afflicted in LD	NA
	Not existing	NE
	≤3 areas involved	1
	3 areas involved	2
	2 areas involved	3
	1 area involved	4
	Tingling disappeared	5
Burning of skin	Not afflicted in LD	NA
	Not existing	NE
	More than 3 areas involved	1
	3 areas involved	2
	2 areas involved	3
	1 area involved	4
	Burning disappeared	5
Tremors of extremities	Not afflicted in LD	NA
	Not existing	NE
	≤3 limbs involved	1
	3 limbs involved	2
	2 limbs involved	3
	1 limb involved	4
	Tremors disappeared	5
Short-term memory	Not afflicted in LD	NA
	Not existing	NE
	No short-term memory at all	1
	Severe short-term memory loss	2
	Moderate short-term memory loss	3
	Mild short-term memory loss	4
	Memory becomes normal	5
Orientation (time, place, person, situation)	Not afflicted in LD	NA
	Not existing	NE
	No orientation for all 4 categories	1
	3 of the 4 categories affected	2
	2 of the 4 categories affected	3
	1 of the 4 categories (mostly time) affected	4
	Orientation assumed normalcy	5
Depression	Not afflicted in LD	NA
	Not existing	NE
	Severe depression with suicidal tendencies	1
	Severe depression without suicidal tendencies	2
	Moderate depression	3
	Mild depression	4
	No depression	5

Contd...

Appendix 1: Contd...

Parameters	Description	Score
Irritability	Not afflicted in LD	NA
	Not existing	NE
	Most of waking hours	1
	Only if in company with people	2
	Only if in company with certain people	3
	Only off and on	4
Bowel-sensation	Irritability disappeared	5
	Not afflicted in LD	NA
	Not existing	NE
	No sensation	1
Bowel-control	Bowel-sensation restored	5
	Not afflicted in LD	NA
	Not existing	NE
Bladder-sensation	No control	1
	Bowel-control restored	5
	Not afflicted in LD	NA
	Not existing	NE
Bladder-control	No sensation	1
	Bladder-sensation restored	5
	Not afflicted in LD	NA
	Not existing	NE
Sleep disorder-hypersomnia	No control	1
	Bladder-control restored	5
	Not afflicted in LD	NA
	Not existing	NE
	>13 h sleep/day	1
	11-13 h sleep/day	2
Sleep disorder-hyposomnia	9-11 h sleep/day	3
	8-9 h sleep/day	4
	Hypersomnia disappeared	5
	Not afflicted in LD	NA
	Not existing	NE
	No sleep despite sleeping medicines	1
Speech	<4 h sleep with medicines	2
	4-6 h sleep with medicines	3
	6-8 h sleep with medicine	4
	Hyposomnia disappeared, i.e., normal sleep with no medicines	5
	Not afflicted in LD	NA
	Not existing	NE
Pain	Depending on alternate communication system	1
	Disarticulated and cannot be understood	2
	Disarticulated but can be understood	3
	Slurred but still understandable	4
	Normal speech	5
Group-2: Musculoskeletal Impairments(areas affected: Upper/lower extremities, back, chest)		
Pain	Not afflicted in LD	NA
	Not existing	NE
	More than 3 areas involved	1
	3 areas involved	2
	2 areas involved	3
	1 area involved	4
Pain disappeared	5	

Contd...

Appendix 1: Contd...

Parameters	Description	Score
Pain-intensity and-type (stabbing, prickling, tearing, pressure)	Not afflicted in LD	NA
	Not existing	NE
	Very severe permanent pain	1
	Severe permanent pain	2
	Moderate and intermittent pain	3
	Mild intermittent pain	4
	Pain disappeared	5
Stiffness of muscles	Not afflicted in LD	NA
	Not existing	NE
	≤3 areas involved	1
	3 areas involved	2
	2 areas involved	3
	1 area involved	4
	Stiffness disappeared	5
Paralysis of upper/lower extremities	Not afflicted in LD	NA
	Not existing	NE
	≤3 limbs involved	1
	3 limbs involved	2
	2 limbs involved	3
	1 limb involved	4
	Paralysis disappeared	5
Fatigue	Not afflicted in LD	NA
	Not existing	NE
	Permanent exhausting fatigue	1
	Fatigue after daily hygiene activities	2
	Fatigue after all normal daily activities	3
	Fatigue after only gentle workout	4
	No fatigue	5
Sitting balance	Not afflicted in LD	NA
	Not existing	NE
	No sitting balance at all	1
	Requires maximum external support	2
	Requires minimum external support	3
	Sits with no external support	4
	Sitting balance normal	5
Sitting-time	Not afflicted in LD	NA
	Not existing	NE
	Sitting for a few min	1
	Sitting for <1 h	2
	Sitting for 1-2 h	3
	Sitting for 2-3 h	4
	Normal	5
Standing balance with calliper	Not afflicted in LD	NA
	Not existing	NE
	Cannot stand at all	1
	Stand with caliper + maximum therapist support	2
	Stand with caliper + minimum therapist support	3
	Stand independently with caliper/with external support	4
	Stand normally without caliper	5

Contd...

Appendix 1: Contd...

Parameters	Description	Score
Standing-time	Not afflicted in LD	NA
	Not existing	NE
	Unable to stand for <5 min	1
	Standing for <10 min	2
	10-30 min	3
	>30 min to 1 h	4
	Standing independently for a long time	5
Walking with aid	Not afflicted in LD	NA
	Not existing	NE
	Walker with elbow support (without wheels)	1
	Walker alone (with wheels)	2
	Elbow crutches	3
	Cane	4
	No walking aid required	5
Walking distance	Not afflicted in LD	NA
	Not existing	NE
	≥5 m/cannot walk alone	1
	Can walk up to 25 m only	2
	Can walk from 50-100 m only	3
	Can walk >100 m up to <500 m only	4
	Can walk normal distances	5
Calipers for standing	Not afflicted in LD	NA
	Not existing	NE
	THKAFO	1
	HKAFO	2
	KAFO+/shanon brace	3
	AFO+/knee brace/shanon brace	4
	Without AFO/knee brace/shanon brace	5
Myalgia	Not afflicted in LD	NA
	Not existing	NE
	Constant muscle pain in the whole body all day and night despite medication	1
	Pain in limbs (U/L, L/L) and/or trunk despite medication	2
	Low pain only in the limbs or trunk as relieved by medication	3
	Slight muscle pain only after exertion	4
	Myalgia disappeared	5

Group-3: Sensory organ afflictions and others

Sensory organ afflictions	Sensitivity to light	Not afflicted in LD	NA	
		Not existing	NE	
		Hypersensitivity to any light	1	
		Hypersensitivity to room light	2	
		Hypersensitivity to sunlight	3	
		Hypersensitivity to bright flashy light only	4	
		Hypersensitivity to light disappeared	5	
		Vision	Not afflicted in LD	NA
			Not existing	NE
			No P/L	1
Blurring with only P/L	2			
Blurred vision	3			
	Blurred vision in the dawn	4		
	Vision becomes normal	5		

Contd...

Appendix 1: Contd...

Parameters	Description	Score
Nystagmus or squint	Not afflicted in LD	NA
	Not existing	NE
	Inability to focus and see clearly	1
	Nystagmus and squint	2
	Nystagmus without squint	3
	Nystagmus with no vision problem	4
Hearing	Nystagmus disappeared	5
	Not afflicted in LD	NA
	Not existing	NE
	Complete hearing loss	1
	Substantial decrease in hearing in both ears	2
	Substantial decrease in hearing in one ear	3
Tinnitus	Mild decrease in hearing	4
	Hearing becomes normal	5
	Not afflicted in LD	NA
	Not existing	NE
	Constant in both ears	1
	Intermittent in both ears	2
Cardiac and respiratory symptoms Heart-palpitations	Constant in one ear	3
	Intermittent in one ear	4
	Tinnitus disappeared	5
	Not afflicted in LD	NA
	Not existing	NE
	Constant palpitations	1
Gastrointestinal symptoms Allergy to food	Several episodes of palpitations during the day and/or night	2
	Every day or night at least 1 episode of palpitations (i.e., awakening by palpitations)	3
	At least 1 episode of palpitations/week	4
	Palpitations disappeared	5
	Not afflicted in LD	NA
	Not existing	NE
Appetite	Allergy to most of the foodstuff	1
	Allergy to dairy products, meat and gluten	2
	Allergy to either 2 of the below: Dairy products/meat/gluten	3
	Allergy to one of the below: Dairy products/meat/gluten	4
	Food allergy disappeared	5
	Not afflicted in LD	NA
Appetite	Not existing	NE
	No appetite at all	1
	Decreased appetite (not eating even 1 meal/day)	2
	Decreased appetite (not eating 2 meals/day)	3
	Decreased appetite on and off	4
	Normal appetite	5

Contd...

Appendix 1: Contd...

Parameters	Description	Score
Unintended weight loss	Not afflicted in LD	NA
	Not existing	NE
	>20 kg/year	1
	>5 kg/month	2
	3-5 kg/month	3
	1-3 kg/month	4
Unintended weight gain	No weight loss	5
	Not afflicted in LD	NA
	Not existing	NE
	>20 kg/year	1
	>5 kg/month	2
	3-5 kg/month	3
Swallowing	1-3 kg/month	4
	No weight gain	5
	Not afflicted in LD	NA
	Not existing	NE
	On peg feeding	1
	Only liquid food by mouth	2
Constipation	Only pureed food by mouth	3
	Semi-solid food by mouth	4
	Swallowing is normal	5
	Not afflicted in LD	NA
	Not existing	NE
	>3 times for week	1
Diarrhea	2-3 times/week	2
	<2 times/week	3
	Hard stool daily	4
	Constipation disappeared	5
	Not afflicted in LD	NA
	Not existing	NE
Other symptoms	Continuously, needing medication	1
	Daily	2
	Every alternate day	3
	Off and on	4
	None	5
	Hair loss during LD	Not afflicted in LD
Not existing		NE
Total baldness		1
Central thinning/patchy thinning		2
Thinning on the sides		3
Hair falls with no baldness		4
Other infections (URTI, UTI, typhoid, malaria, not yet recognized co-infections of LD etc.)	Hair loss stopped	5
	Not afflicted in LD	NA
	Not existing	NE
	Takes 100 % longer to recover than normal (with medication)	1
	Takes >50 % longer to recover with medication	2
	Takes >10% longer to recover with medication	3
	Takes slightly longer than normal to recover with medication	4
	Takes normal time to recover	5

LD: Lyme disease, P/L: Perception of light, AFO: Ankle-foot-orthosis, KAFO: Knee-ankle-foot-orthosis, HKAFO: Hip-knee-ankle-foot orthosis, THKAFO: Trunk-hip-knee-ankle-foot orthoses, NE: Not existing, NA: Not afflicted, URTI: Upper respiratory tract infection, URI: Urinary tract infection, U/L: Upper limb, L/L: Lower limb