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ORIGINAL ARTICLE

Tele-assessment in limb-girdle muscular dystrophy: feasibility and reliability of patient-led asynchronous method

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Abstract

Objective This study aimed to investigate the feasibility and reliability of the six assessment tools commonly used in limb-girdle muscular dystrophy (LGMD) for patient-led asynchronous method: Brooke Scale, Vignos Scale, Fatigue Severity Scale (FSS), Numeric Rating Scale for Pain (NRS-Pain), Modified Barthel Index (MBI), and Nottingham Health Profile (NHP).

Methods This study included 40 individuals with LGMD (55% female; mean age = 30.53 ± 9.68 years). The assessment tools used in the study were initially completed by the participants using the patient-led asynchronous method and one week later using the clinician-led synchronous method. Google Forms was utilized for the patient-led asynchronous method, and ZoomTM was used for the clinician-led synchronous method. Furthermore, a questionnaire created by the researchers was administered to assess the satisfaction and usefulness of the procedures of both tele-assessment methods.

Results There was no significant difference between the total scores of the six assessment tools obtained by both methods (p's > 0.05). Intraclass correlation coefficients (ICC) exhibited excellent reliability for the total scores of the FSS (ICC = 0.91), MBI (ICC = 0.92), and NHP (ICC = 0.87). Weighted kappa (κw) showed excellent reliability for the Brooke Scale (κw = 0.94) and Vignos Scale (κw = 0.94), and good reliability for the NRS-Pain (κw = 0.63). The questionnaire conducted on the satisfaction and usefulness of the procedure of tele-assessment methods showed significantly greater overall satisfaction with the clinician-led synchronous method ($p = 0.009$).

Conclusion In individuals with LGMD, the six assessment tools were feasible and reliable when utilized with the patient-led asynchronous method.

Keywords Limb-girdle muscular dystrophy · Telemedicine · Physiotherapy · Functional capacity · Reliability

Abbreviations

LGMD	Limb-Girdle Muscular Dystrophy
FSS	Fatigue Severity Scale
NRS-Pain	Numeric Rating Scale for Pain
MBI	Modified Barthel Index
NHP	Nottingham Health Profile
NMD	Neuromuscular Disease
ICC	Intraclass Correlation Coefficient
MDC_{95}	Minimal Detectable Change with 95% Confidence Interval
SEM	Standard Error of Measurement
κw	Weighted Kappa
ENMC	European Neuromuscular Centre

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Introduction

Limb-Girdle Muscular Dystrophy (LGMD) is a rare, progressive, and autosomal inherited neuromuscular disease that mainly results in proximal muscle weakness but also leads to distal muscle weakness as the disease progresses [1]. LGMD, which causes a gradual loss of muscle mass and function, may adversely affect independent living and, ultimately, quality of life and overall well-being [2]. Access to healthcare services is challenging due to a scarcity of health professionals who specialize in this disease, as well as the wide geographical distribution and disability status of individuals with LGMD [3]. Additionally, the COVID-19 pandemic, which has caused global upheaval, further aggravated the challenges of accessing healthcare services and created an urgent need to design new models for healthcare delivery to avoid face-to-face consultation and reduce the risk of contamination [4, 5]. Tele-health has emerged as an innovative solution to deal with all these challenges limiting access to healthcare services in individuals with neuromuscular diseases (NMDs) [5, 6]. However, research in tele-health has primarily focused on remote intervention, leaving tele-assessment in the shadows [7].

Tele-assessment, which offers numerous advantages in terms of efficacy, cost-effectiveness, and accessibility, enables the periodic assessment of individuals remotely in clinical practice and research using information and communication technologies [8]. Tele-assessment can be mainly classified as synchronous and asynchronous. While the synchronous method allows real-time communication between patient and clinician through means such as video conferencing, the asynchronous method allows communication without the need for real-time interaction through means such as e-mail [9]. Tele-assessment is encouraging in several diseases, such as musculoskeletal disorders, stroke, Parkinson's disease, and multiple sclerosis [10]. However, to the best of our knowledge, there is no study addressing tele-assessment in individuals with NMDs, which could be a crucial option in ensuring the continuity of health services.

The psychometric properties of assessment tools in face-to-face settings have been extensively addressed in the literature; however, further research is necessary to examine the psychometric properties of assessment tools when used in tele-assessment, which can ensure the quality and accuracy of tele-assessment [11, 12]. Recently, the 266th European Neuromuscular Centre (ENMC) International Workshop also highlighted the need to validate remote clinical assessments and optimize their implementation in neuromuscular populations. The workshop underscored that tele-assessment methods should be integrated into routine clinical and research practice for rare NMDs [13]. Therefore, the current study aimed to determine whether the six assessment tools commonly used in LGMD are feasible and reliable when used with patient-led asynchronous tele-assessment.

Methods

This methodological study was carried out between May 2022 and August 2022. The study was approved by the ethics committee of Lokman Hekim University (April 18, 2022, decision no: 2022/7) and conducted in accordance with the Helsinki Declaration. Prior to recruitment in the study, all participants were informed about the objective and scope of the study, and they signed an informed consent form.

Patients

The study was conducted with individuals with LGMD, who were reached using the method of snowball sampling from the members of the Turkey Limb-Girdle Muscular Dystrophy Society. The inclusion criteria were: (1) having an LGMD diagnosis confirmed by a neurologist; (2) having materials such as laptops and tablets for using online assessment methods; (3) being over 18 years old; and (4) being literate. Exclusion criteria were: (1) having difficulty with cooperation and (2) being at the 6th level on the Brooke Scale.

Procedure

For the patient-led asynchronous method, the assessment tools were converted into an online survey form via the Google Form platform. For the clinician-led synchronous method, Zoom™ (California, United States) video communication software was installed on the portable computer (MacBook Pro, Model A1502, Apple Inc., California, United States), and a special Zoom™ account was created for the study. Before starting the study, a video conference training was organized for all participants on the use of Google Forms and Zoom™. The assessment tools used in the study were initially completed by the participants using the patient-led asynchronous method and one week later using the online physiotherapist-led synchronous method under the supervision of a physiotherapist who was blinded to the participants' first assessments (Fig. 1).

Assessment tools

The following criteria guided the selection of the assessment tools: special equipment-free, simple, easily understandable, and utilized in both ambulatory and non-ambulatory individuals [14]. Furthermore, assessment tools were selected that address parameters widely used in NMDs [11], such as

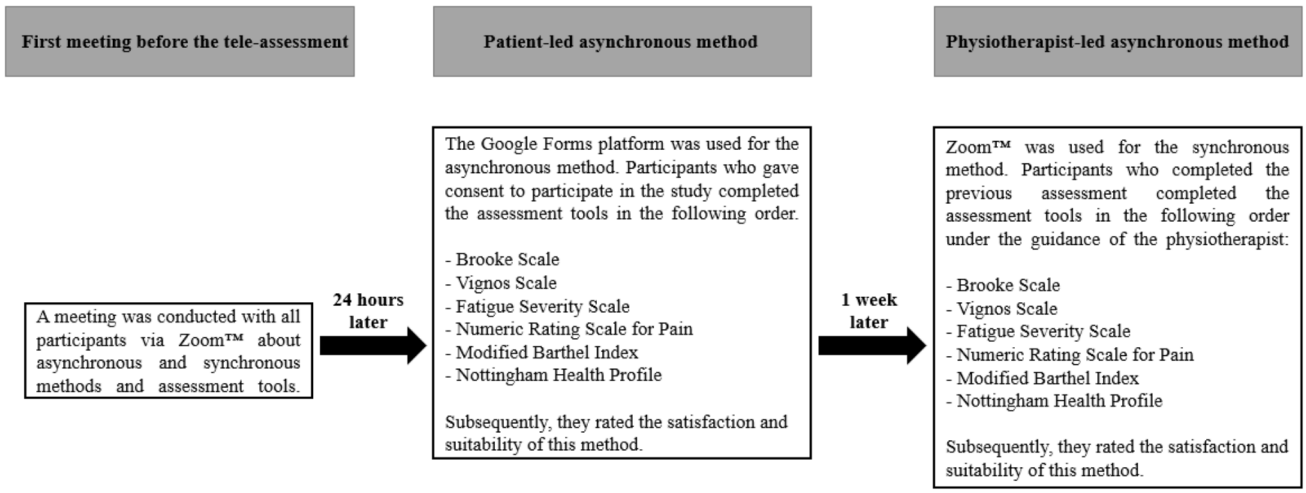

Fig. 1 Study procedure

upper limb functional capacity, ambulation, fatigue, pain, activities of daily living, and quality of life. The Brooke Scale, Vignos Scale, Fatigue Severity Scale (FSS), Numeric Rating Scale for Pain (NRS-Pain), Modified Barthel Index (MBI), and Nottingham Health Profile (NHP) were used to assess the functionality of upper extremity, ambulation, fatigue, pain, activities of daily living, and quality of life, respectively. In contrast to the Fatigue Severity Scale (FSS), Numeric Rating Scale for Pain (NRS-Pain), and Nottingham Health Profile (NHP), the Brooke Scale, Vignos Scale, and Modified Barthel Index (MBI) are not inherently self-reported tools. However, all assessment tools in this study were scored via self-report due to the remote and asynchronous nature of data collection. Furthermore, a questionnaire created by the researchers was used to assess the feasibility of the tele-assessment methods.

Brooke scale

The Brooke Scale is a valuable tool for assessing upper extremity function in NMDs. It grades upper extremity function from 1 to 6, with the higher the grade, the poorer the upper extremity function [15]. The scale is a practical and valid tool used to follow the disease progression in NMDs [16]. Since involvement of the shoulder girdle muscles is frequently observed in individuals with LGMD, we preferred to evaluate the upper extremity function using the Brooke Scale.

Vignos scale

It grades individuals on a scale of 1 to 10, from the ability to walk and climb stairs without assistance to being completely bedridden. The Vignos Scale has been widely used due to its simplicity and effectiveness in evaluating the lower extremity functions and ambulation status of NMDs [17, 18]. As the involvement of the pelvic girdle muscles is common in individuals with LGMD, we selected to assess lower extremity function and ambulation status using the Vignos Scale.

Fatigue severity scale (FSS)

The FSS, a self-report questionnaire that assesses the fatigue severity over the past 1 week, consists of 9 items, and each item is rated on a scale of 1–7, with higher values representing a greater level of fatigue [19]. Because fatigue is a common symptom in various NMDs, impacting quality of life and functional ability [20], we decided to assess fatigue severity using the FSS.

Numeric rating scale for pain (NRS-Pain)

It is a widely used tool for assessing pain intensity in individuals with various health conditions, including those with NMDs. The NRS typically ranges from 0 to 10, where 0 represents no pain and 10 indicates the worst possible pain [21]. As pain is reported as a major common symptom that may be seen in most NMDs [22], we used the NRS-Pain to measure pain intensity.

Modified Barthel index (MBI)

It is a commonly used tool to evaluate the functional independence and activities of daily living in various populations, like NMDs. The MBI consists of 10 items that evaluate an individual's ability to execute fundamental activities like feeding, bathing, and dressing. It has a score range of 0 to 100, where higher values represent improved functional independence and the ability to carry out daily

activities without assistance [23]. NMDs can lead to limitations in performing daily living activities due to muscle weakness, fatigue, pain, and impaired motor function [24]. Thus, we used MBI to assess functional independence.

Nottingham health profile (NHP)

It is a self-reported questionnaire that assesses health-related quality of life in terms of physical, emotional, and social aspects. The NHP has 6 subscales that evaluate energy, pain, emotional reactions, sleep, social isolation, and physical mobility. Each subscale ranges between 0 and 100, while the total score (NSP-Total) ranges between 0 and 600. Higher scores indicate a greater impact on health and well-being [25].

Feasibility measures

After the completion of both tele-assessment methods, a questionnaire created by the researchers based on a systematic review [26] was administered to measure the satisfaction and usefulness of the procedure of patient-led asynchronous and clinician-led synchronous methods in the current study. The questionnaire consisted of 6 items on overall satisfaction, cost-effectiveness, time efficiency, security of personal information, ease of use, and innovative status. To assess the perception of satisfaction, participants were requested to rate each item using a numerical rating scale ranging from 0 to 10, with higher values representing a greater level of satisfaction.

Statistical analysis

All statistical analysis was conducted using the IBM SPSS Statistics for Windows v26.0 (SPSS Inc., Chicago, USA). The normal distribution of continuous variables was examined using visual (histogram and probability graphs) and analytical methods (Shapiro–Wilk test, skewness and kurtosis values, and coefficient of variation). The reliability of the total scores of the FSS, MBI, and NHP obtained by the patient-led asynchronous and physiotherapist-led synchronous methods was examined with intraclass correlation coefficient (ICC) values using the two-way random model. ICC values greater than 0.75 were interpreted as excellent agreement [27]. The standard error of measurement (SEM) and the minimal detectable change with a 95% confidence interval (MDC_{95}) were calculated to ensure the accuracy of the measurement methods. The value of ICC was employed to estimate the SEM and then to estimate the MDC_{95}. The MDC_{95} was calculated by multiplying the SEM by 1.96 and the square root of 2 to adjust for sampling from 2 different measurements. Because the MDC_{95} value varies depending on the test unit, the results were interpreted using the percent value of the MDC_{95}, and <30% of the mean score was settled as acceptable [28]. For the reliability of ordinal variables such as the NRS-Pain score, a linear-weighted Kappa (κw) coefficient was used. They were interpreted according to Landis and Koch [29]: excellent (>0.80), good (0.60–0.80), moderate (0.40–0.60), fair (0.20–0.40), and poor (≤0.20). In the comparison of the difference between the two tele-assessment methods, the Paired Sample T Test was used as a parametric test, and the Wilcoxon Signed-Rank Test was used as a non-parametric test. Furthermore, the effect size was calculated to determine the magnitude of change between the two tele-assessment methods. Effect size values; below 0.30 were interpreted as a small effect, between 0.30 and 0.50 as a medium effect, and at 0.50 and above as a large effect [30]. A p-value less than 0.05 was determined as an indicator of statistical significance.

The sample size and post-hoc power analysis were performed with the R Studio (packages 'semPower' and 'ICC.sample.size', R Core Team, 2022). Based on the estimated intraclass correlation coefficient (ICC) = 0.9, number of ratings = 2, power = 80%, and $\alpha = 0.05$, the sample size was determined as 33. Given the potential dropout rate (20%), 40 participants were included in the study. With a statistical significance of $\alpha = 0.05$, obtained ICC = 0.91, 0.92, and 0.87, and sample size = 40, the post-hoc powers (1-β) were found to be 99.9%, 99.9%, and 97.9% for the FSS, MBI, and NHP, respectively.

Results

Seventy-five individuals initially consented to participate in the study; however, 35 were excluded from the analysis (14 due to being under 18 years of age and 21 due to the absence of a confirmed diagnosis), resulting in a final sample of 40 participants with LGMD (55% female; mean age = 30.53 ± 9.68 years). There were not any dropouts in the present study. LGMD R1(2 A) accounted for 37.5% of the participants, LGMD R2 (2B) for 25%, LGMD R5 (2 C) for 7.5%, LGMD R3 (2D) for 10%, LGMD R4 (2E) for 17.5%, and LGMD R7 (2G) for 2.5%. The means of ages at the onset of the symptoms and at the time of definitive diagnosis were 14.05 ± 4.97 and 21.88 ± 8.60 years, respectively. The demographic and clinical features are presented in Table 1.

There was no significant difference between the mean total scores of the FSS, MBI, and NHP (Table 2) and median scores of the Brooke Scale, Vignos Scale, and NRS-Pain (Table 3) obtained by the patient-led asynchronous and physiotherapist-led synchronous methods (p's > 0.05). The effect sizes of the differences between the two assessment methods ranged between 0.06 and 0.29, which indicates that

Table 1 The demographic and clinical characteristics of the individuals with LGMD ($n=40$)

Variables		x̄ ± SD	min-max
Age (years)		30.53 ± 9.68	18–58
Age at definitive diagnosis (years)		21.88 ± 8.60	8–40
Age at onset of symptoms (years)		14.05 ± 4.97	6–28
		n	**%**
Gender	**Male**	18	45
	Female	22	55
Subtypes of LGMD	**R1/2A**	15	37.50
	R2/2B	10	25
	R5/2C	3	7.50
	R3/2D	4	10
	R4/2E	7	17.50
	R7/2G	1	2.50
Brooke Scale (Level)	**1**	15	37.50
	2	8	20
	3	13	32.50
	4	2	5
	5	2	5
Vignos Scale (Level)	**1**	2	5
	2	12	30
	3	3	7.50
	4	5	12.50
	5	4	10
	6	3	7.50
	7	3	7.50
	8	8	20
	9	2	5

x̄: mean, SD: standard deviation, n: number, %: frequency, min: minimum, max: maximum,

LGMD: Limb-Girdle Muscular Dystrophy

they are small. The total scores of the FSS (ICC = 0.91), MBI (ICC = 0.92), and NHP (ICC = 0.87) obtained by patient-led asynchronous methods exhibited excellent reliability (Table 2). The MDC_{95} percent was less than 30% for FSS and MBI, yet it is over 30% for NHP. While the scores of the Brooke Scale (κw = 0.94) and Vignos Scale (κw = 0.94) showed excellent reliability, NRS-Pain (κw = 0.63) showed good reliability (Table 3).

Table 4 Feasibility results of the tele-assessment methods

Feasibility measures	Patient-led asynchronous	Clinician-led synchronous	*p*
Overall satisfaction	8.65 ± 2.38	9.37 ± 1.23	**0.041**
Cost-effectiveness	8.65 ± 2.47	9.70 ± 0.91	**0.008**
Time efficiency	8.73 ± 2.42	9.63 ± 1.00	**0.017**
Security of personal information	8.43 ± 2.42	9.38 ± 1.35	**0.004**
Ease of use	8.70 ± 2.39	9.57 ± 1.11	**0.009**
İnnovative status	8.77 ± 2.41	9.73 ± 0.91	**0.007**
Total score	51.93 ± 14.25	57.38 ± 5.54	**0.009**

Values are given as mean ± SD. p: Paired T Test

The questionnaire conducted on the satisfaction and usefulness of the procedure of tele-assessment methods showed significantly greater satisfaction with the clinician-led synchronous method in terms of overall satisfaction, cost-effectiveness, time efficiency, security of personal information, ease of use, and innovation (p's < 0.05). However, the mean feasibility measures of the procedures for both tele-assessment methods were relatively high, considering the maximum possible score was 60 (patient-led asynchronous method = 51.93 ± 14.25; clinician-led synchronous method = 57.38 ± 5.54; $p=0.009$) (Table 4).

Discussion

To our knowledge, this is the first study on the feasibility and reliability of a tele-assessment method in individuals with LGMD. Given the insufficient number of health professionals specialized in this disease, as well as the wide

Table 2 Reliability results of the tele-assessment methods for the total scores of FSS, MBI, and NHP

	Patient-led asynchronous x̄ ± SD	Clinician-led synchronous x̄ ± SD	Δ (95% CI)	*p*	EF	ICC (%95 CI)	SEM	MDC_{95} (%)
FSS	41.73 ± 15.53	42.15 ± 14.44	0.43 (-1.68/2.53)	0.68	0.06	0.91 (0.83/0.95)	4.50	12.41 (20.15)
MBI	70.38 ± 18.51	71.87 ± 15.68	1.50 (-0.71/3.71)	0.17	0.21	0.92 (0.85/0.96)	4.85	13.38 (12.82)
NHP	173.3 ± 108.81	184.97 ± 106.8	11.67 (-5.73/29.07)	0.18	0.21	0.87 (0.77/0.93)	38.87	107.20 (40.77)

x̄: mean, SD: standard deviation, p: Paired Sample T Test, Δ: the mean difference obtained by subtracting patient-led asynchronous from the clinician-led synchronous method, EF: Cohen's effect size, SEM: standard error of mean, MDC: minimal detectable change, ICC: intraclass correlation coefficient, CI: confidence interval, FSS: Fatigue Severity Scale, NRS-Pain: Numeric Raiting Scale for Pain, MBI: Modified Barthel Index, NHP: Nottingham Health Profile

Table 3 Reliability results of the tele-assessment methods for Brooke scale. Vignos scale. And NRS-Pain

	Patient-led asynchronous	Clinician-led synchronous	*p*	EF	κw (95% CI)
Brooke Scale	2 (1/3)	2 (1/3)	0.180	0.21	0.94 (0.85/1.00)
Vignos Scale	5 (2/8)	4.5 (2/8)	0.066	0.29	0.94 (0.87/1.00)
NRS-Pain	2 (1/5)	3 (1/4.75)	0.459	0.12	0.63 (0.44/0.81)

Values obtained by tele-assessment methods are given as median (25th/75th centile). p: Wilcoxon Signed-Rank Test. EF: effect size. κw: weighted kappa coefficient. CI: confidence interval

geographical distribution and disability status of individuals with LGMD, this is remarkable. The results revealed that the six assessment tools commonly used in individuals with LGMD exhibit good-to-excellent reliability and promising feasibility when administered with patient-led asynchronous methods.

Tele-assessment and assessment parameters in neuromuscular diseases

Tele-health, a topic of interest for a long time, experienced a great development with the outbreak of the COVID-19 pandemic, which was critical for the sustainability of healthcare services. Tele-health has gained substantial acceptance in physiotherapy and rehabilitation, as well as in other health disciplines [10, 31]. Yet, research in tele-health has primarily focused on remote interventions, such as cardiorespiratory, musculoskeletal, and neurologic rehabilitation practices, and tele-assessment has lagged behind [7, 32]. Since tele-assessment plays a vital role in managing the interventions, it should be kept in mind that the validity and reliability of tele-assessment methods are addressed initially [31].

In the systematic review conducted by Zischke et al. in 2021, it was noted that studies in the field of tele-assessment addressed various populations, such as musculoskeletal disorders, stroke, Parkinson's disease, cardiorespiratory diseases and different assessment parameters, such as range of motion, muscle strength, endurance, special orthopedic tests, balance, and functional performance. The authors emphasized that tele-assessment appears valid and reliable for specific assessment parameters in limited populations [10]. In conclusion, it is noteworthy that no study addresses a special group such as LGMD, which is rare and has a wide geographical distribution, as well as assessment parameters such as fatigue, activities of daily living, and quality of life, all of which were addressed in the current study.

Although some authors recommend the use of tele-assessment methods in neuromuscular diseases (NMDs), this recommendation is based on expert opinions rather than research evidence [5, 6, 33]. However, recent international efforts have been made to bridge this gap. Notably, the 266th ENMC International Workshop emphasized the importance of validating remote clinical assessment tools and proactively planning for the integration of tele-assessment in both clinical care and research for individuals with NMDs [13]. Our findings are consistent with this expert consensus, providing empirical support for the feasibility and reliability of remote assessment tools in a patient-led asynchronous format for individuals with LGMD.

Fatigue, an underestimated aspect of NMDs for a long time, affects a wide range of individuals with NMDs [34]. In the current study, it was found that FSS had excellent reliability and feasibility when administered with patient-led asynchronous methods to individuals with LGMD. Chronic pain, another common symptom in NMDs, has been reported to affect approximately 45% of individuals with LGMD, and it often occurs in the waist, neck, shoulders, hips, and legs [35]. In our study, the NRS-Pain demonstrated good reliability, in contrast to other assessment tools that showed excellent reliability when administered with patient-led asynchronous methods. This could be explained by variations in pain localization and intensity experienced over the day, changes in pain between two assessment time points, and the questioning of general body pain rather than regional pain in our study. Therefore, future studies should consider localization as well as intensity in pain assessment.

The Brooke and Vignos scales, which are popular assessment tools for grading upper extremity functionality and ambulation status in NMDs [16], were both found to have excellent reliability when administered with patient-led asynchronous methods to individuals with LGMD. Other assessment parameters covered in this study, independence in daily living activities and quality of life, have a significant impact on the overall health and everyday functioning of individuals with NMDS [36]. The MBI and NHP, which addressed these two essential assessment parameters, were found to have excellent reliability when administered with patient-led asynchronous methods to individuals with LGMD.

Asynchronous tele-assessment method

Asynchronous tele-assessment provides several benefits in healthcare delivery. It offers cost-effective solutions, particularly for accessing underserved locations where healthcare professionals are scarce. Asynchronous methods allow the patient and clinician to respond at their convenience and standardized and structured data collection. However, there are significant drawbacks associated with asynchronous tele-assessment. Challenges such as miscommunication, limited feedback, and suspicion about assessment results due to lack of real-time interaction can impede the effectiveness of this method, which should be taken into account when using asynchronous tele-assessment [12, 37].

Gomes Costa et al. studied the usability of performance-based muscle strength assessment with asynchronous and synchronous tele-assessment in individuals with spinal cord injury. They reported that the results of asynchronous tele-assessment showed excellent reliability (ICC = 0.86) with synchronous tele-assessment [38]. Oliveira et al. addressed the reliability of a self-report assessment tool for activity and participation restrictions in chronic stroke patients using tele-assessment and found that asynchronous teleassessment showed adequate reliability (ICC = 0.66) with

face-to-face administration [39]. Onal et al. examined the reliability of a performance-based balance scale when used with tele-assessment in chronic stroke patients and noted excellent reliability (ICC = 0.98) between face-to-face and asynchronous methods [40]. These studies, which focused on diverse populations and assessment tools with varying characteristics, reported that the asynchronous tele-assessment method was reliable, which is in line with our findings.

Strengths, limitations, and future directions

Before beginning the study, we provided training to inform the participants about the assessment tools and use of tele-assessment methods used in the study, which may be a critical point for the results to be more reliable. Therefore, we recommend that health professionals who will use the tele-assessment methods initially provide training to individuals about the assessment tools and the use of the preferred tele- assessment methods. Furthermore, we believe it is valuable that assessment tools such as the MBI, Brooke Scale, and Vignos Scale, which provide important information to researchers about independent living and categorize the current functionality, were found to be reliable and feasible when administered with patient-led asynchronous methods in individuals with LGMD. With the asynchronous assessment method including these 3 assessment tools, regular follow-up can be performed and information about the involvement and prognosis of the individuals with LGMD can be obtained.

The most challenging issue we encountered before the study was deciding what assessment tools to utilize. Based on the literature, we established certain selection criteria: special equipment-free, simple, easily understandable, and utilized in both ambulatory and non-ambulatory individuals. Moreover, assessment tools that address parameters commonly used in NMDs, such as upper extremity functional capacity, ambulation, fatigue, pain, activities of daily living, and quality of life, were selected [11, 14].

The current study has limitations that should be considered in future studies. As the COVID-19 pandemic was ongoing and individuals with LGMD resided in various locations, the number of participants available for face-to-face assessment was insufficient. Thus, we had to compare the patient-led asynchronous method with the clinician-led synchronous method instead of face-to-face assessment. In addition, snowball sampling was used to include individuals from the Turkey Limb-Girdle Muscular Dystrophy Society, which may weaken the generalizability of the findings and the representativeness of the sample. Another important limitation concerns the administration of the Brooke Scale, Vignos Scale, and MBI. Although these tools are traditionally clinician-administered and require direct observation or performance-based scoring, in the current study they were scored via self-report, with participants rating their own functional status. This adaptation was necessary due to the asynchronous tele-assessment design, yet it may have introduced potential bias, particularly for items that require specific physical environments (e.g., stairs) or time-based performance. Therefore, results from these tools should be interpreted with caution. We encourage future research to explore the validation of self-reported scoring methods for these functional assessment tools.

Conclusion

The research findings reveal that the six assessment tools frequently used in individuals with LGMD were reliable and feasible when administered with patient-led asynchronous methods, which offers a promising avenue for the assessment, monitoring of the disease progression, and ultimately planning of the interventions.

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Author contributions M.B. was responsible for data acquisition, analysis, and interpretation of the data, and drafted the article. H.I.C, A.A.K. participated in data acquisition, analysis, and interpretation of the data, and was a major contributor in writing the article. M.B. was responsible for the conception and design of the study, participated in the acquisition, analysis, and interpretation of the data, and was a major contributor in writing the article. All authors contributed to the critical review and revision of the article. All authors read and approved the final version of the article.

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Data availability The data that support the findings of this study are available from the corresponding author upon reasonable request.

Declarations

Ethics approval and consent to participate The study was approved by the ethics committee of Lokman Hekim University (April 18, 2022, decision no: 2022/7) and all procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Consent for publication Not applicable.

Competing interests The authors have no conflicts of interest to declare that are relevant to the content of this article.

Consent to participate All individuals provided written informed consent to participate in the study.

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