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Food literacy among Portuguese adults with skeletal dysplasia: insights from a cross-sectional study

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Abstract

Purpose Skeletal dysplasias are a heterogeneous group of 771 rare diagnoses, that present short stature as a common feature. Despite the importance of nutrition in health management, food literacy in this population remains largely unexplored. This study aimed to assess the level of food literacy among Portuguese adults with skeletal dysplasia.

Methods A cross-sectional observational study was conducted among adults (> 18 years) with skeletal dysplasia ($n = 43$, 30 female). Data were collected through an online questionnaire comprising two sections: sociodemographic and clinical information and the Portuguese version of the Food Literacy Scale (FLS). The FLS covers three dimensions: literacy about the nutritional composition of food, literacy about labelling and food choices, and literacy about healthy eating practices. Food literacy scores were calculated as percentage indices. Descriptive statistics with 95% confidence intervals and subgroup comparison by sex and age were performed.

Results Mean overall food literacy score was 60.8% (CI 95%: 54.7–66.9). Among the three dimensions, the highest mean score was observed for healthy eating practices, 62.0% (CI 95%: 56.4–67.6), and the lowest for labelling and food choices, 59.0% (CI 95%: 51.1–66.9). No statistically significant differences were found in overall food literacy or in any of its dimensions according to sex or age. Participants reported greater difficulty with recommended protein amounts, interpreting and using food labels, adhering to the Mediterranean diet, and recommended portion sizes.

Conclusions Adults with skeletal dysplasia in Portugal showed modest food literacy scores, mainly in domains related to food labelling and food choices. Tailored nutrition education strategies and more easily accessible food-related guidance may help address the specific literacy gaps identified in this population.

Keywords Rare bone disease, Achondroplasia, Osteogenesis imperfecta, Food literacy

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Introduction

Skeletal dysplasias or osteochondrodysplasias encompass a highly heterogeneous group of 771 rare bone disorders that predominantly affect the development, structure, and composition of bones, cartilage, and dentin [18]. These conditions can be diagnosed during the perinatal period or only in adulthood. Among the various skeletal dysplasias, short stature is the most frequent and impactful clinical feature [10, 18]. Based on the latest National Registry of Congenital Anomalies report (2018–2019), skeletal dysplasias affect approximately 1.6 per 10,000 live births in Portugal. In 2018, the incidence of the coding" osteochondrodysplasias of long bones and spine" (coding Q77 of the International Disease classification, ICD-10) was 8 births and for other osteochondrodysplasias was 6 births per 10,000 live births [5]. Considering there were 87,020 live births in 2018 in Portugal, the estimated incidence of skeletal dysplasias in Portugal is of 0.4 cases per 10,000 live births [5]. With a population of 10.7 million habitants, we can estimate that between 800 and 1000 people in Portugal have a skeletal dysplasia [6, 14].

Several types of skeletal dysplasia are frequently associated with comorbidities such as obesity, respiratory pathology, early-onset degenerative joint disease, and reduced physical fitness. These long-term health challenges require active self-management, including informed lifestyle and dietary decisions. In this context, food literacy may represent an important factor in enabling individuals to make appropriate food choices and adopt healthier dietary behaviours [3]. The concept of food literacy was empirically defined and analysed by Helen Vidgen and Danielle Gallegos in 2014 [19] as "the scaffolding that empowers individuals, households, communities or nations to protect diet quality through change and strengthen dietary resilience over time. It is composed of a collection of inter-related knowledge, skills and behaviours required to plan, manage, select, prepare and eat food to meet needs and determine intake." Within this broader framework, nutrition literacy is often considered a domain-specific application of health literacy in the context of food and nutrition. One of the earliest definitions was proposed by Julie L. Blitstein and William D. Evans [4], who described nutrition literacy as the capacity to obtain, process, and understand basic nutrition information needed to make appropriate nutrition decisions. Subsequent studies have further developed this concept, emphasizing the importance of skills that enable individuals to access, interpret, and apply nutrition information in everyday food choices [20]. Food literacy has been identified as a key individual trait that can promote healthy and sustainable dietary patterns, and programs targeting food literacy have been shown to improve knowledge and skills for making healthier food choices and adopting better eating behaviours [2]. Although literature on food and nutrition literacy among the Portuguese population is limited, a study by Monteiro et al. [12] revealed that 65.2% of Portuguese adults ($n = 338$, 85.2% female and 14.8% male, with a mean age of 33.5 years) had a good level of nutrition literacy [12]. Within this framework, and recognizing the importance of food literacy, its characterization within this specific population will be useful for designing more targeted interventions to improve dietary quality and the nutritional management of comorbidities. This is especially relevant, as no studies to date have assessed food literacy levels in this population. The objectives of this study were, firstly, to assess the level of food literacy among adults with skeletal dysplasia living in Portugal; and secondly, to explore whether food literacy scores differed according to sex and age. Understanding which domains of food literacy are less understood among adults with skeletal dysplasia may inform the design of more tailored, needs-based interventions. These interventions could aim to improve food literacy, including knowledge, skills, and behaviours related to planning, selecting, preparing, and consuming food, and thereby support healthier dietary choices.

Methods

Study design

This cross-sectional observational study evaluated food literacy among adults with skeletal dysplasia living in Portugal. An online questionnaire was developed in collaboration with the National Association for Skeletal Dysplasias (ANDO) and disseminated using Google Forms between May and June 2024, through email and social media.

Participants

Eligible participants were adults aged 18 years or older, living in Portugal and reporting a diagnosis of skeletal dysplasia. Participants reporting non-skeletal dysplasia conditions (e.g., fibromyalgia) or unable to specify their exact diagnosis ($n = 13$) were excluded, resulting in a final sample size of 43 participants. The study was approved by the Ethics Committee of Polytechnic University of Leiria, approval number 50/2024. All participants provided informed consent prior to completion of the questionnaire.

Research instrument and data collection

The questionnaire comprised two sections. The first was a tailored sociodemographic and clinical information section, including age, gender, education level, income, physical activity habits, specific dietary pattern, place of residence, professional status, and clinical history context; Sociodemographic variables were obtained using closed-ended questions with predefined categorical responses or ordinal intervals, while dietary patterns

and clinical information were collected using open-ended questions. Participants were also asked to indicate whether they followed any specific dietary pattern (e.g., vegetarian, lactose or gluten-free). Responses were coded and categorized for analysis. Age was recorded as a continuous variable and later grouped into categories for descriptive and subgroup analysis.

The second section comprised the Portuguese Food Literacy Scale (FLS), validated in Portuguese university students [8]. The scale assesses three dimensions across 26 items: literacy about nutritional composition of foods, literacy about labelling and food choices, and literacy about healthy eating practices, as shown in Table 1. To calculate the food literacy index, we have followed the methodology proposed by Guiné et al. [9], where each item was scored on a 5-point scale (1 = very difficult, 2 = difficult, 3 = easy, 4 = very easy, 5 = I don't know) and the answers corresponding to 5 (I don't know) were excluded from the analysis. For each participant, dimension scores were summed and converted into percentage values relative to the maximum possible score, with the same procedure applied to calculate overall food literacy.

Statistical analysis

Data were analysed using SPSS, version 29.0.1.0. A power analysis ($\alpha = 0.05$) informed that approximately 64 participants per group would be needed for a two-sided independent t-test with 80% power to detect medium-sized effects for a total sample size of 128. Having a sample of $n = 43$, the study was underpowered, only able to detect large effect sizes ($d \approx 0.88$). Descriptive statistics included means and standard deviations, 95% confidence intervals, and absolute and relative frequencies. Normality was assessed using the Shapiro-Wilk test. Group difference analyses were limited to sex and age for being more interpretable than other grouping variables under the presented sample size. Income, education level, region, and frequency of physical activity were analysed for descriptive sample characterization. Independent-samples t-tests were used for sex and one-way ANOVA for age-group comparisons, with statistical significance set at $p < 0.05$.

Results

A total of 43 adults with skeletal dysplasia were included in the analysis, among whom 69.8% (30/43) were female. The most represented age group was 36–45 years (30.2%,13/43). Only 16.3% (7/43) participants had a lower monthly income below €820. Most had high education qualifications (22/43 had a university degree), with 32.6% (14/43) living in the Centre region of the country and 27.9% (12/43) living in the capital, Lisbon.

Table 1 Dimensions and items included in the food literacy scale

Dimension 1 - Literacy about the nutritional composition of foods	1	Understand the information contained in the Portuguese Food Wheel
	2	Find information on the nutritional quality of beverages
	3	Use the information to match your daily fluid intake needs
	4	Understand the usefulness of taking food supplements (multivitamins, vitamins, calcium, omega 3, etc.)
	5	Find information on the differences between saturated and unsaturated fats
	6	Understand the effects resulting from the consumption of saturated and unsaturated fats
	7	Understand the type of carbohydrates you eat in your diet
	8	Understand the benefits or drawbacks of excessive consumption of dietary fiber
	9	Understand the recommended amounts for protein
	10	Moderate protein intake
Dimension 2 - Literacy about labelling and food choices	11	Understand the recommendations on the amounts of food that should be consumed, when presented in mass (grams)
	12	Find information about the Mediterranean diet
	13	Practice eating habits that conform to the standards of the Mediterranean diet
	14	Find information on how to interpret food labels
	15	Find information about the nutritional semaphore on food labels
	16	Understand the nutritional semaphore on food labels
	17	Use food labelling to help make healthier food choices
Dimension 3 - Literacy about healthy eating practices	18	Find information on healthy eating (website of the General Health Directory—DGS) (official Portuguese website)
	19	Find information on healthy eating (internet; television; books/magazines)
	20	Understand information on healthy eating (DGS website)
	21	Find information on daily meal frequency
	22	Understand the importance of eating several times a day
	23	Find information on diets and regimes (calorie restriction; vegetarian/vegan; organic; diets suitable for certain diseases/intolerances (e.g., gluten-free))
	24	Understand the information about diets found on the internet
	25	Find information on recommended portion sizes for each type of food
	26	Understand recommendations on the amounts of food that should be consumed, when presented in portions

Also, 55.8% (24/43) reported no regular physical activity. Most participants (90.7%, 39/43) did not report following a specific dietary pattern. Key sociodemographic characteristics of the study sample are summarized in Table 2. Regarding skeletal dysplasia types, more than 50% of participants (22/43) had either Achondroplasia or Osteogenesis imperfecta. Most participants (28/43) did not report comorbidities, as presented in Table 3.

Table 4 shows the response distribution for each FLS item. The highest proportion of "*Don't know*" responses was observed for the item on finding information about healthy eating on the DGS website, selected by

Table 2 Sociodemographic characteristics of participants (total *n* = 43)

Sociodemographic Characteristics	*n*	%
Sex		
Male	13	30.2
Female	30	69.8
Age		
18–25	11	25.6
26–35	5	11.6
36–45	13	30.2
46–54	11	25.6
> 55	3	7.0
Income		
Below 820€	7	16.3
820€-1640€	10	23.3
1640€-2460€	8	18.6
2460€-3280€	4	9.3
Above 3280€	8	18.6
Doesn´t respond	6	14.0
Professional activity		
Active worker	26	60.5
Student	9	20.9
Unemployed	3	7.0
Retired	3	7.0
Working student	2	4.7
Education		
Elementar	2	4.7
Highschool	18	41.9
University	22	51.2
Others	1	2.3
Region		
North	5	11.6
Center	14	32.6
West and Tejo Valley	3	7.0
Lisbon	12	27.9
Setúbal Peninsula	3	7.0
Alentejo	3	7.0
Azores	1	2.3
Algarve	2	4.7
Physical Activity		
0 days/week	24	55.8
1–2 days/week	17	39.5
3–4 days/week	2	4.7
Specific dietary pattern		
Vegan diet	1	2.3
Lactose-free diet	2	4.7
Gluten-free diet	1	2.3
No specific dietary pattern	39	90.7

Percentages are rounded to one decimal place; therefore, totals may not equal exactly 100%

Table 3 Types of skeletal dysplasia and comorbidities (total participants = 43)

Skeletal Dysplasia	*n*	%
Achondroplasia	13	30.2
Osteogenesis imperfecta	9	20.9
Multiple epiphyiseal dysplasia	6	14
Diastrophic dysplasia	4	9.3
X-linked hypophosphatemia	4	9.3
Spondyloepiphyseal dysplasia Kimberley type	1	2.3
Cartilage-hair hypoplasia	1	2.3
Pseudoachondroplasia	1	2.3
Congenital spondyloepiphyseal dyplasia	1	2.3
Type 2 Collagenopathies	1	2.3
Aggrecam mutation	1	2.3
Metaphyseal chondrodysplasia, Schmid type	1	2.3
Comorbidities		
None	28	65.1
High blood pressure	6	14
High cholesterol	4	9.3
Mental disorder	3	7
Asthma	1	2.3
Obesity	1	2.3

Percentages are rounded to one decimal place; therefore, totals may not equal exactly 100%

30.2% (13/43) of participants. At item level, the greatest reported difficulties concerned understanding recommended amounts for protein, finding and using food-label information, practising eating habits consistent with the Mediterranean diet, and identifying appropriate portion sizes.

Mean overall food literacy was 60.8% (SD 20.2; 95% CI 54.7–66.9). Among the three dimensions, the highest mean score was observed for healthy eating practices, 62.0% (SD 18.4; 95% CI 56.4–67.6), while the lowest was observed for labelling and food choices, 59.0% (SD 25.9; 95% CI 51.1–66.9). Literacy about the nutritional composition of foods showed a mean score of 60.8% (SD 21.3; 95% CI 54.3–67.3). The overall results of this study, regarding food literacy dimensions and overall food literacy are summarized in Table 5. There were no statistically significant differences observed in overall food literacy or its dimensions according to sex or age. Given the small and fragmented sample, no inferential group comparisons were presented for income, education level, region, or physical activity frequency.

Discussion

This study provides initial evidence on food literacy among Portuguese adults with skeletal dysplasia, a population for whom nutrition-related self-management may be especially relevant because several skeletal dysplasias are associated with obesity, respiratory pathology, joint disease, and reduced physical fitness [3, 15]. The mean overall food literacy score observed in this sample was lower (60.7%) than that reported by Guiné et al. (80.22%) in Portuguese university students (736 female and 188 males, 22.35 ± 6,10 years) using the same instrument [9], suggesting that adults with skeletal dysplasia may face additional barriers in accessing, understanding, or applying food-related information. Nevertheless, no differences in food literacy were found according to sex or age in the study by Guiné et al., a finding consistent with our results.

The scarcity of research and tailored follow-up guidelines for skeletal dysplasia further exacerbates this challenge, as individuals and healthcare professionals lack access to condition-specific, evidence-based resources [7]. This limited information landscape likely contributes to the low food literacy observed, as well as to difficulties in self-management and disease-related decision-making [17].

Our results highlight areas of nutritional literacy that should be emphasised for this population. In dimension 1, 55.8% (24/43) of participants found it very difficult or difficult to understand the recommended amounts for protein. Within dimension 2, two closely related items—finding information about the nutritional semaphore on food labels and using this information to make healthier food choices—were reported as difficult or very difficult by the highest proportions of participants, 39.5% (17/43) and 37.3% (16/43), respectively. In dimension 3, two related items stood out as the most challenging: finding information on recommended portion sizes for each type of food was reported as difficult or very difficult by 48.9% (21/43) of participants, and understanding recommendations on the amounts of food to be consumed, when

Table 4 Responses per each item of the FLS

			Don´t Know	Very Difficult	Difficult	Easy	Very Easy
Dimension 1	1	Understand the information contained in the Portuguese Food Wheel	0 (0.0%)	0 (0.0%)	2 (4.7%)	25 (58.1%)	16 (37.2%)
	2	Find information on the nutritional quality of beverages	3 (7.0%)	0 (0.0%)	10 (23.3%)	23 (53.5%)	7 (16.3%)
	3	Use the information to match your daily fluid intake needs	7 (16.3%)	0 (0.0%)	13 (30.2%)	20 (46.5%)	3 (7.0%)
	4	Understand the usefulness of taking food supplements (Multivitamins, vitamins, calcium, Omega 3, etc.,)	5 (11.6%)	1 (2.3%)	6 (14.0%)	27 (62.8%)	4 (9.3%)
	5	Find information on the differences between saturated and unsaturated fats	9 (20.9%)	3 (7.0%)	11 (25.6%)	14 (32.6%)	6 (14.0%)
	6	Understand the effects resulting from the consumption of saturated and unsaturated fats	8 (18.6%)	4 (9.3%)	10 (23.3%)	14 (32.6%)	7 (16.3%)
	7	Understand the type of carbohydrates you eat in your diet	6 (14.0%)	4 (9.3%)	12 (27.9%)	16 (37.2%)	5 (11.6%)
	8	Understand the benefits or drawbacks of excessive consumption of dietary fiber	5 (11.6%)	2 (4.7%)	10 (23.3%)	20 (46.5%)	6 (14.0%)
	9	Understand the recommended amounts for protein	4 (9.3%)	5 (11.6%)	19 (44.2%)	11 (25.6%)	4 (9.3%)
	10	Moderate protein intake	5 (11.6%)	2 (4.7%)	15 (34.9%)	17 (39.5%)	4 (9.3%)
Dimension 2	11	Understand the recommendations on the amounts of food that should be consumed, when presented in mass (grams)	5 (11.6%)	3 (7.0%)	11 (25.6%)	18 (41.9%)	6 (14.0%)
	12	Find information about the Mediterranean diet	6 (14.0%)	2 (4.7%)	10 (23.3%)	18 (41.9%)	7 (16.3%)
	13	Practice eating habits that conform to the standards of the Mediterranean diet	6 (14.0%)	5 (11.6%)	11 (25.6%)	17 (39.5%)	4 (9.3%)
	14	Find information on how to interpret food labels	4 (9.3%)	4 (9.3%)	11 (25.6%)	17 (39.5%)	7 (16.3%)
	15	Find information about the nutritional semaphore on food labels	6 (14.0%)	1 (2.3%)	16 (37.2%)	13 (30.2%)	7 (16.3%)
	16	Understand the nutritional semaphore on food labels	6 (14.0%)	0 (0.0%)	14 (32.6%)	16 (37.2%)	7 (16.3%)
	17	Use food labelling to help make healthier food choices	5 (11.6%)	2 (4.7%)	14 (32.6%)	17 (39.5%)	5 (11.6%)
Dimension 3	18	Find information on healthy eating (website of the General Health Directory—DGS)—official Portuguese website)	13 (30.2%)	1 (2.3%)	11 (25.6%)	12 (27.9%)	6 (14.0%)
	19	Find information on healthy eating (internet; television; books/magazines)	2 (4.7%)	1 (2.3%)	7 (16.3%)	27 (62.8%)	6 (14.0%)
	20	Understand information on healthy eating (DGS website)	1 (2.3%)	2 (4.7%)	7 (16.3%)	27 (62.8%)	6 (14.0%)
	21	Find information on daily meal frequency	4 (9.3%)	5 (11.6%)	9 (20.9%)	20 (46.5%)	5 (11.6%)
	22	Understand the importance of eating several times a day	1 (2.3%)	0 (0.0%)	8 (18.6%)	23 (53.5%)	11 (25.6%)
	23	Find information on diets and regimes (calorie restriction; vegetarian/vegan; organic; diets suitable for certain diseases/intolerances (e, g,, gluten-free))	6 (14.0%)	3 (7.0%)	9 (20.9%)	20 (46.5%)	5 (11.6%)
	24	Understand the information about diets found on the internet	3 (7.0%)	1 (2.3%)	13 (30.2%)	23 (53.5%)	3 (7.0%)
	25	Find information on recommended portion sizes for each type of food	3 (7.0%)	2 (4.7%)	19 (44.2%)	15 (34.9%)	4 (9.3%)
	26	Understand recommendations on the amounts of food that should be consumed, when presented in portions	5 (11.6%)	4 (9.3%)	16 (37.2%)	14 (32.6%)	4 (9.3%)

Results presented as counts and percentage

Table 5 Mean percentage scores for the three food literacy dimensions and for overall food literacy

	Mean (%)	Standard Deviation (%)	95% CI (%)
Dimension 1	60.8	21.3	54.3–67.3
Dimension 2	59.0	25.9	51.1–66.9
Dimension 3	62.0	18.4	56.4–67.6
Overall food literacy	60.8	20.2	54.7–66.9

Confidence intervals for mean were calculated using the t-distribution based on sample estimates

presented in portions, was reported as difficult or very difficult by 46.5% (20/43) of participants.

Such difficulties may hinder the adoption of a healthier diet, particularly adherence to the Mediterranean diet, which has been extensively associated with health promotion and better management of metabolic comorbidities [11, 13, 16]. Importantly, 37.2% (16/43) of participants found very difficult or difficult to practice eating habits that conform to the standards of the Mediterranean diet. In addition, inadequate ability to select appropriate food portions can negatively impact dietary habits and complicate the control of prevalent comorbidities in this population, including dyslipidemia and/or hypertension, also present in 23.3% (10/43) of our participants.

While no statistically significant differences were found according to sex or age, the estimates and 95% confidence intervals enable exploratory observations.

Likely, disease-specific barriers, such as unique nutritional needs, physical limitations, or lack of targeted educational materials, may play a more decisive role than general education in shaping food literacy among adults with skeletal dysplasia [17]. It is also worth noting that most participants did not engage in regular physical activity, which may further hinder the adoption of a healthier lifestyle and food choices [1].

Moreover, it is important to highlight that questionnaires frequently include a "Don't know" option, which, despite being used to avoid random answers, can be interpreted in two distinct ways: either as a genuine absence of knowledge or uncertainty regarding the most suitable option. Although we followed the original scale as recommended, the exclusion of this option from the overall food literacy calculation may represent a limitation of the instrument itself, potentially leading to overestimation of food literacy levels or reflecting challenges in assessing certain aspects of food literacy rather than true knowledge gaps.

This study also has important limitations. The study was small, justified by the rarity of these conditions, yet this poses challenges for group inference and allows the detection only of large effects, which are likely also due to insufficient power rather than the absence of real differences. In addition, although the Food Literacy Scale has been validated in university student populations, its use in a heterogeneous adult population with skeletal dysplasia represents a limitation of this study, so measurement validity in this context remains uncertain. This may affect the generalisability and measurement validity of the findings, highlighting the need for further validation in diverse adult populations. And excluding the 'Don't know' responses from the score calculation may have inflated observed literacy levels or masked uncertainty, which is itself meaningful.

Conclusions

This sample of Portuguese adults with skeletal dysplasia showed modest food literacy scores, highlighting needs for targeted interventions. The identification of specific food literacy gaps, such as difficulties in adopting a Mediterranean diet and selecting appropriate food portions, can guide the development of tailored strategies aimed at improving dietary behaviours and overall health outcomes in this population.

Future studies should validate adapted tools and explore longitudinal impacts on health outcomes. Advocacy organizations and healthcare professionals should develop tailored education programs to improve dietary behaviours, potentially reducing comorbidities in this vulnerable group.

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Author contributions
B.G., R.C., V. D. and P.J. created the form for data collection. B.G., I.A. and C.D.P., analyzed the data, wrote the main manuscript text and B.G. prepared the tables. All authors reviewed the manuscript.

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Data availability
No datasets were generated or analysed during the current study.

Declarations

Ethics approval and consent to participate
The study was approved by the Ethics Committee of Polytechnical University of Leiria, approval number 50/2024.

Consent to participate
All participants provided informed consent to participate prior responding to the questionnaire.

Consent for publication
Not applicable.

Competing interests
The authors declare no competing interests.

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