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Effectiveness of an Intervention Program for Informal Carers of Children Admitted to a Rehabilitation Centre

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Abstract

Health literacy improves informal caregivers' knowledge and ability to provide care. The aim of this study is to analyze the impact of a group-based intervention on the health literacy of informal caregivers of children with special health needs (SHNs). The intervention focuses on movement, hydrotherapy, walking, and relaxation, with three evaluation stages. Participants included 34 informal caregivers of children with SHNs, recruited at a Physical Medicine and Rehabilitation Service. We collected sociodemographic data of the participants and measured their health literacy through the short-form version of the European Health Literacy Survey Questionnaire (HLS-EU-Q16). Around 70% of the participants were female, with a mean age of 41.06 ± 4.98 years, and nearly 85% were married or in a de facto union. About 26% were unemployed, and more than 65% had completed secondary education or higher. The mean scores of the HLS-EU-Q16 were statistically significantly higher throughout the intervention, with differences over the evaluation stages [F(2,56) = 75.55; $p < 0.05$]. A structured, dynamic, and group-based intervention plan showed improvements in the health literacy of the participants, with an increase in the percentage of participants with sufficient and excellent levels of health literacy at the end of the intervention.

Keywords: informal caregivers; health literacy; physical activity

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1. Introduction

According to UNICEF [1], children with special health needs (SHNs) are those with health problems whose condition may include: (a) those who were born with a pathology that affects their development; (b) those who have suffered a lifelong injury, infection or nutritional deficiency that contributes to long-term dysfunction; (c) those who have been exposed to environmental toxins that result in developmental delays; and (d) those who have developed anxiety or depression as a result of limiting events. The increasing prevalence of these situations has led to a rise in dependency cases within this population, often requiring the dedicated support of informal caregivers [2].

In Portugal, the Statute of the Informal Caregiver (Law no. 100/2019, 6 September) defines an informal caregiver as "the spouse, de facto partner or relative up to the fourth degree of the person being cared for, who permanently accompanies and cares for him/her, lives in a shared residence, and does not receive any payment for professional activity or the care provided to the person" [3].

The demanding nature of caregiving often leads to significant personal sacrifice. Informal caregivers frequently experience feelings of isolation and neglect their own well-being and basic needs, which can result in considerable mental and physical health problems [4,5]. For these caregivers, enhanced knowledge and health literacy are crucial. Better-informed caregivers are more capable of making conscious and well-considered decisions, ultimately improving the quality of life for the individuals they care for [6]. Indeed, health literacy is a topic of growing importance in public health and healthcare, recognizing its role in empowering individuals to manage their health effectively [7,8].

In 2012, the European Health Literacy Consortium introduced a comprehensive definition of health literacy that states: "Health literacy is linked to literacy and entails people's knowledge, motivation and competences to access, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course" [8]. Individuals with low health literacy often experience more hospitalizations, increased emergency care usage, underutilization of preventive services, difficulty interpreting health information, poorer health, higher mortality, and increased healthcare expenditures [9,10].

Informal caregivers of children with SHN face multiple challenges that require special knowledge to fulfill their role effectively. Providing them with social recognition and appreciation is important to ensure they receive the necessary support for more effective and sustainable care. It is essential to invest in their training and provide professional, legal, and financial assistance [2].

Despite efforts to integrate informal caregivers into support systems and improve the care they provide, significant gaps remain. A study on informal caregivers revealed that 65% cited restrictions on their personal and social lives as a major challenge, followed by health limitations (42%), lack of time (39%), and insufficient personal or technical support (38%). Additionally, 33% reported financial difficulties, and 30% experienced challenges in their relationship with the dependent person. Over 40% identified in-home support, technical aids, and free time as their most pressing needs [11]. These unmet needs underscore the necessity of developing targeted plans and strategies to address them [12,13].

In the literature, most studies focus on caregivers of the adult population, and there is a distinct lack of specific activity programs designed for informal caregivers of children with SHNs. To bridge this gap and align with Portuguese informal caregiver guidelines, a survey was conducted to identify the perceived needs and difficulties within this specific population. This research directly informed the development of the intervention project 'Cuide+ de Si' (Take better care of yourself).

Through this program, it is expected that the informal caregiver will acquire knowledge that promotes the improvement of their health literacy, benefiting both themselves and their dependents. The intervention was designed to help caregivers develop greater awareness of their physical and emotional state. By participating in activities, the connection between physical exercise and the production of neuromediators (such as endorphins, serotonin, and dopamine [14]) promoted their overall well-being [15]. We aimed to encourage intentional adoption of practical self-care strategies (e.g., energy conservation techniques, proper postures) and strengthen their ability to understand, apply, and share health information, given the group dynamic. The intervention consists of a group-based plan with thematic interventions—movement, hydrotherapy, walking, and relaxation. According to Mahindru et al. [15], physical activity has significant positive effects on mental health, including reducing anxiety and depression, boosting self-esteem, and improving mood and general well-being. These factors create more favorable conditions for acquiring new knowledge and developing the cognitive and emotional skills essential for health literacy. Thus, by promoting caregivers' emotional balance and well-being through physical activity and relaxation, the intervention indirectly but significantly enhances their capacity to comprehend and utilize health information more autonomously and consciously.

The primary objective of this study is to assess the impact of the intervention on the health literacy of informal caregivers of children with SHN. Secondary objectives include the characterization of informal caregivers based on their sociodemographic characteristics and examination of the relationship between these characteristics and health literacy levels.

2. Materials and Methods

2.1. Type of Study and Data Source

The study is characterized as quasi-experimental, utilizing a single intervention group to facilitate causal inference. Descriptive analysis was performed on the health literacy levels of the study population, in addition to an exploration of their correlation with sociodemographic data. Data collection occurred in 2024 within the Pediatrics Department of the Physical Medicine and Rehabilitation Service at the North Rehabilitation Center, which is part of the Local Health Unit of Vila Nova de Gaia/Espinho.

2.2. Study Population

The study population consisted of all informal caregivers of children admitted to this unit. It included all informal caregivers of children admitted to the unit who agreed to participate, ensuring everyone had an equal probability of inclusion. The inclusion criteria were: the person cared for was aged 17 years or younger, and participants did not present any physical activity-limiting pathology. The exclusion criteria were: the cared-for person was aged 18 years or older, or the participant had any physical activity-limiting pathology. Informed consent was obtained from all participants.

2.3. Procedures and Intervention Design

The design of the intervention was centered on four key areas:

i. Physical exercise (movement) that promotes changes in body structure and function, preventing various pathologies (e.g., diabetes, cardiovascular diseases), and improving physical health, mental health, and quality of life [16–19];
ii. Hydrotherapy through physical exercise in water induces physiological changes in body systems due to hydrostatic and hydrodynamic pressure. Benefits include improved balance, motor coordination, and increased muscle strength [20,21];
iii. Beyond its sustainable component, walking improves the cardiovascular system and increases flexibility, as noted by Schmidt et al. [21];
iv. Relaxation through less impactful, calmer interventions promotes whole-body work focused on resistance, flexibility, and mental strength [22].

For the intervention's implementation, approval was secured from the Clinical Board of the North Rehabilitation Center and the Ethics Committee of the Local Health Unit of Vila Nova de Gaia/Espinho (approval document no. CES 32/2024-1, dated 4 June 2024).

The questionnaires were administered in three stages: initial (S0), after 6 weeks of the intervention (S1), and at the end of the program (S2), which was determined by the dependent's hospital discharge. At S0, participants also completed a sociodemographic characterization form and informed consent.

The intervention was led by physiotherapists, with more than ten years of experience working with children and their caregivers, and involved bi-weekly sessions organized into thematic cycles: one week of movement (physical exercise), one of hydrotherapy, one of walking, and one of relaxation.

2.4. Measurement Instruments

To achieve the study's objective, a questionnaire was developed to collect sociodemographic data from informal caregivers, including age, sex, employment status, education, and marital status. It also gathered information about the cared-for person's age, sex, and relationship to the caregiver.

The European Health Literacy Survey Questionnaire (HLS-EU) was originally created in 2012 [23]. A short-form version was developed in 2016 [7], the HLS-EU-Q16 [24], with good internal consistency (Cronbach's alpha = 0.89). We selected the HLS-EU-Q16 as the health literacy assessment instrument for this population.

The HLS-EU-Q16 measures health literacy levels based on an individual's self-perception across three domains: healthcare, health prevention, and health promotion. The classification of overall health literacy and the descriptive analysis of its dimensions followed the methodology proposed by Sørensen et al. [23]. These domains are assessed through 16 items [7], each with a response range from 'very difficult' to 'very easy,' indicating the perceived difficulty of performing a specific task. The obtained values are standardized according to Pelikan et al. [25], making the instrument scores range from 0 to 50 with the following levels, for total and for dimensions: inadequate from 0 to 25; problematic from 25.1 to 33; sufficient from 33.1 to 42; and excellent from 42.1 to 50.

2.5. Data Analysis

After collecting the completed questionnaires, data were analyzed using IBM SPSS® Statistics 29, with a significance level of 5% considered.

We performed a quantitative analysis of the responses. For both the sociodemographic data and the questionnaires at each time point (S0, S1, S2), a descriptive analysis was conducted, presenting frequencies, means, maximums, minimums, and standard deviations.

Regarding internal consistency, Cronbach's alpha values between 0.70 and 0.79 were considered acceptable, and values higher than 0.80 were deemed adequate [26,27].

Before conducting any parametric tests, we ensured that the necessary assumptions were met. Normality was assessed using the Kolmogorov–Smirnov test for sample sizes (N) of 30 or greater, and the Shapiro–Wilk test for N less than 30. Homogeneity of population variances was verified using Levene's test.

To compare the three evaluation stages (S0, S1, S2), we used the mean values of the total scores. We initially verified the assumptions of normality and sphericity, then performed an ANOVA for repeated measures. If statistically significant differences were found between stages, a Sidak post hoc test was conducted.

Finally, to compare the results from each scale with sociodemographic data, we used the Pearson correlation test for total scores (S0, S1, and S2) and age. The chi-square test was applied to compare the categorized total scores (S0, S1, and S2) with the education level.

3. Results

3.1. Sample Size

During the collection stage, out of 38 informal caregivers with children hospitalized, 34 agreed to participate in the program. Of the 34 informal caregivers, all completed the first two evaluation stages (S0 and S1), with 29 completing the third stage (S2).

On average, caregivers participated in the project for 14 weeks, with a maximum duration of 29 weeks.

3.2. Sample Characterization

Table 1 presents the sociodemographic data of the study population. Around 70% (N = 24) of the sample were female, aged between 25 and 59 (41.06 ± 4.98) years, and 85.3% were married or in a de facto union. Regarding employment status, 73.5% were employed. All participants had some level of education, with 70.6% having completed secondary education or higher.

Table 1. Sociodemographic data of informal caregivers.

Variables		N (%)
Sex	Female	24 (70.6%)
	Male	10 (29.4%)
Age	Mean ± standard deviation	41.06 ± 4.98
	Min–Max	25–59
Marital status	De facto union	5 (14.7%)
	Married	24 (70.6%)
	Divorced	3 (8.8%)
	Widowed	2 (5.9%)
Employment status	Employed	25 (73.5%)
	Unemployed	9 (26.5%)
Education	Lower Secondary Education	3 (8.8%)
	Upper Secondary Education	7 (20.6%)
	Secondary Education	12 (35.3%)
	Bachelor's Degree	7 (20.6%)
	Postgraduate	2 (5.9%)
	Master's Degree	2 (5.9%)
	Doctoral Degree	1 (2.9%)

3.3. Results of the HLS-EU-Q16

The HLS-EU-Q16 presented a good internal reliability (Cronbach's $\alpha = 0.759$).

As demonstrated in Table 2, over the three evaluation stages, the scale scores showed an increasing trend: S0 with an average score of 30.36, S1 with a value of 37.19, and S2 with a value of 43.14.

Table 2. HLS-EU-Q16 scores at three evaluation stages.

	Minimum	Maximum	Mean	Standard Deviation
Stage 0	16.67	44.79	30.36	6.93
Stage 1	29.17	50.00	37.19	4.98
Stage 2	32.29	50.00	43.14	4.98

Stage 0: beginning of the intervention; Stage 1: 6 weeks after the beginning of the intervention; Stage 2: end of the intervention.

Analyzing the health literacy levels, presented in Table 3, there was a continuous increase over the three evaluation stages. Stage 0 was the only one where an inadequate level was found, and there were mostly problematic levels of health literacy. Stage 1 predominantly presented 'sufficient' levels, and Stage 2 presented 'excellent' levels in more than half of the sample.

Table 3. Health literacy levels at three evaluation stages.

Health Literacy Levels	S0 N (%)	S1 N (%)	S2 N (%)
Inadequate	7 (20.6%)	-	-
Problematic	15 (44.1%)	7 (20.6%)	1 (3.4%)
Sufficient	10 (29.4%)	23 (67.6%)	11 (37.9%)
Excellent	2 (5.9%)	4 (11.8%)	17(58.6%)

S0: beginning of the intervention; S1: 6 weeks after the beginning of the intervention; S2: end of the intervention.

Regarding the three domains, it was observed that the healthcare domain consistently exhibited the lowest health literacy levels across all stages (problematic at S0 and sufficient at S1 and S2) when compared to the other domains. At Stages 0 and 2, the disease prevention domain showed the highest average levels (sufficient and excellent, respectively), whereas at Stage 1, the health promotion domain had the highest average (sufficient). These results are presented in Table 4.

Table 4. Mean scores of health literacy for each domain, at three evaluation stages.

Health Literacy Domain	S0 Mean (sd)	S1 Mean (sd)	S2 Mean (sd)
Global health literacy	30.36 (6.93)	37.19 (4.98)	43.14 (4.98)
Healthcare	25.77 (9.80)	34.10 (8.51)	40.80 (6.26)
Disease prevention	34.51 (8.16)	38.73 (7.29)	45.06 (5.95)
Health promotion	33.21 (10.23)	40.69 (6.89)	44.83 (6.17)

sd: standard deviation; S0: beginning of the intervention; S1: 6 weeks after the beginning of the intervention; S2: end of the intervention.

A repeated measures ANOVA test was performed, which revealed statistically significant differences in health literacy levels between the evaluation stages [F(2,56) = 75.55; $p < 0.05$]. The Sidak post hoc test further indicated statistically significant differences ($p < 0.001$) between all stages. These statistical test results are presented in Table 5.

Table 5. Comparison of HLS-EU-Q16 scores between the three evaluation stages (based on estimated marginal means).

Literacy (I)	Literacy (J)	Mean Difference (I − J)	Standard Deviation	Sig.
S0	S1	−6.36	1.028	<0.001
	S2	−12.21	1.092	<0.001
S1	S0	6.36	1.028	<0.001
	S2	−5.86	0.845	<0.001
S2	S0	12.21	1.092	<0.001
	S1	5.86	0.845	<0.001

S0: beginning of the intervention; S1: 6 weeks after the beginning of the intervention; S2: end of the intervention.

The remaining sociodemographic data did not correlate with the scales, indicating that the characteristics of the present sample did not influence the scores obtained on each scale. Furthermore, program duration also showed no correlation with the scale scores.

4. Discussion

The sociodemographic profile of informal caregivers in this study largely aligns with the existing literature, particularly concerning sex, age, employment status, education level, and their relationship with the dependent child.

This study found that 71% of informal caregivers were women, consistent with the literature indicating that caregiving is a highly gendered activity [28–33]. Despite universal care needs and various gender equality initiatives, the distribution of caregiving tasks remains disproportionate. Society continues to assign and associate the caregiving role primarily with women [28,33]. This disparity acts as a barrier to gender equality and negatively impacts women's employment opportunities, especially at younger ages. Notably, 50% of women in this study remained employed while providing informal care, mirroring findings in both Portuguese and other European populations [28,31–33].

While most reviewed studies report caregiver age in broad ranges (typically between 35 and 64 years [29–33]), the mean age of participants in this study was 41.06 ± 4.98 years, falling in this range. Participants also showed a similar distribution between secondary and higher education levels, consistent with data from the Caring for Informal Caregivers Movement study [32]. We observed that the dependent individuals were minors with an average age of 9 years, predominantly cared for by their parents, an observation consistent with other studies [30,32].

Our intervention was designed to foster greater awareness of physical and emotional well-being among caregivers through their participation in activities. They learn practical self-care strategies (such as energy conservation techniques and proper posture) and strengthen their ability to understand, apply, and share health information within a group dynamic. This hands-on experience directly empowers caregivers to make informed decisions for themselves and in the context of the care they provide.

As Mahindru et al. [15] highlight, physical activity significantly impacts mental health by reducing anxiety and depression, boosting self-esteem, and improving overall mood and well-being. These positive effects create a more receptive state for acquiring new knowledge and developing cognitive and emotional skills essential for health literacy. Therefore, by promoting emotional balance and well-being through physical activity and relaxation, our intervention indirectly but significantly reinforces caregivers' capacity to comprehend and utilize health information more autonomously and consciously.

Health literacy was assessed using the HLS-EU-Q16, revealing a growing trend that indicates continuous improvement in caregivers' ability to understand and use health-related information. The statistically significant differences in health literacy levels across the three evaluation stages confirm the program's effectiveness in promoting these improvements. These differences underscore the importance of a targeted and structured intervention that positively impacts caregivers' capacity to manage children's health conditions.

In the initial health literacy evaluation stage, most caregivers exhibited problematic levels, aligning with the study by Pedro et al. [7]. However, other sources indicate that health literacy levels in the general European and Portuguese population are generally sufficient [34–36]. By the end of the intervention, health literacy levels were predominantly excellent, corroborating the systematic review by Walters et al. [37], which found that educational programs targeting these populations increase health literacy, empowering caregivers with fundamental skills and knowledge for managing the health of the dependents.

According to Pedro et al. [7] and the HLS-EU Consortium [38], the healthcare domain typically presents the highest levels of health literacy. This was not initially observed in our study, where it yielded the lowest scores compared to other European countries. However, a reversal of this trend was noted in the final evaluation stage. Although it was the domain with the lowest scores, the post-intervention values became comparable to the best observed values in other European countries [38].

Participants in our study consistently demonstrated a higher level of literacy in the disease prevention domain across the three evaluation stages. This trend is not commonly reported in the analyzed literature [7,38]. Despite this, the values obtained are comparable to the European average, even though Portugal is among the countries with the lowest literacy index in this domain. Following the intervention, performance in this domain remained the highest, even surpassing the European reference values [38].

Few studies on informal caregivers encompass a broad spectrum and greater variability of pediatric pathologies. This study aims to fill that literature gap by allowing all informal caregivers of children admitted to the physical medicine and rehabilitation service to join the program, regardless of the child's pathology.

Being a caregiver is associated with poor mental health, which can negatively affect the dependent child's well-being, according to Bamber et al. [39]. These authors emphasize the need for practical intervention plans directly involving caregivers to mitigate these potential side effects. Additionally, Ferreira [11] and Sousa et al. [40] highlight the importance of community intervention projects that aim to improve caregiver knowledge, promote social support, and facilitate group dynamics, enabling informal caregivers to share experiences and knowledge.

Häikiö et al. [41] point out another significant reason for increased health literacy: informal caregivers, particularly those of children, frequently represent their dependents in interactions with healthcare professionals. This leads to more frequent exchanges of relevant information, thereby increasing their knowledge. This point is particularly applicable to the informal caregivers in this study, as they are the primary contacts for the multidisciplinary teams.

Low levels of health literacy are associated with a higher number of hospitalizations, increased use of emergency services, less engagement in disease prevention and health promotion, poor self-perceived health, and lower education levels, ultimately leading to a decreased quality of life [11,12,42].

One aim was to determine the relationship between the assessed health literacy domains and the sociodemographic characteristics of the sample. However, despite extensive and sometimes inconsistent literature, only one correlation was found.

The intervention plan, due to its broad scope, allowed the monitoring of the different characteristics of the informal caregivers, mitigating the challenges faced by them. Furthermore, it produced a statistically significant effect in improving their health literacy when comparing the program's initial and final stages.

Other studies should be developed following this work outline, trying to fix the weaknesses discovered during the intervention, investigating whether informal caregivers take their role consciously and voluntarily, and not for lack of another option, exploring the sustainability of the effects obtained in the long term, and even extrapolating it to other groups of informal caregivers.

5. Limitations

Regarding limitations, it is important to highlight the small sample size and variable intervention duration—often due to the child's clinical discharge—may limit the generalizability of our findings. The child's evolving clinical status significantly impacted caregiver participation, as their primary role was to provide assistance.

Furthermore, initial recruitment challenges, such as caregiver fatigue, emotional stress, or communication barriers, may have introduced selection bias. While our multidisciplinary team's intervention helped mitigate these hurdles, we were unable to systematically quantify the reasons for non-participation.

Additionally, the direct relationship between literacy and well-being and quality of life was not studied, which would have provided more information on how the intervention effectiveness depends of health literacy.

6. Conclusions

A structured group exercise and relaxation plan, by fostering body awareness and exercise physiology, and its role in producing well-being, directly encourages self-care and thus improves health literacy.

We recommend conducting further studies based on this design, addressing the identified limitations. Future research should also explore the long-term sustainability of the effects.

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Informed Consent Statement: Informed consent was obtained from all subjects involved in the study.

Data Availability Statement: The authors will make the raw data supporting this article's conclusions available without undue reservation.

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Conflicts of Interest: The authors declare no conflicts of interest.

Abbreviations

The following abbreviations are used in this manuscript:

HLS-EU-Q16	European Health Literacy Survey Questionnaire short-form
S0	Initial stage
S1	After 6 weeks of the program
S2	At the end of the program (depending on hospital discharge)
SHNs	Special health needs

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