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Quality of Life in Children and Adolescents with Celiac Disease in the Russian Federation: Results of the Cross-Sectional Multicenter Study

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Introduction. Assessing the quality of life of patients with various chronic diseases, including celiac disease, is an important component of scientific research, determining the rationale and effectiveness of treatment and rehabilitation strategies. Few studies have examined the quality of life of children with celiac disease on a gluten-free diet. Furthermore, all of these studies utilized a variety of questionnaires.

Aim: to study the quality of life of children and adolescents with celiac disease on a gluten-free diet using a validated Russian-language version of the CD-QOL questionnaire.

Materials and methods. A cross-sectional study surveyed 599 children and adolescents with celiac disease (aged 2–22 years) using a validated Russian-language version of the CD-QOL questionnaire; the impact of diet on social functioning was also assessed. Comparisons were made using Student's *t*-test (Welch's test was used if homogeneity of variances was not met). For age groups, one-way analysis of variance (ANOVA) was used, with a preliminary check for homogeneity of variances using Levene's test; in case of homogeneity, Tukey's *post-hoc* test was performed. In cases of deviations from normality, the nonparametric Mann — Whitney test was used to compare independent groups. Multiple linear regression was used to assess the influence of factors on indicator levels; associations between variables were additionally assessed using the Pearson or Spearman correlation. The significance level was $p < 0.05$.

Results. The mean subscale scores for 599 respondents were: “social-emotional limitations” — 3.39 (SD = 0.96), “anxiety/fear for health” — 3.16 (SD = 1.07). A moderately strong positive correlation was found between the subscales ($r = 0.649$; $p < 0.001$). No gender differences were found ($p = 0.956$ and $p = 0.970$ for both subscales). In the analysis by age groups, a statistical trend was observed for the “limitations” component (ANOVA: $F(3,590) = 2.63$; $p = 0.053$). For the anxiety component, with confirmed homogeneity of variances using Levene’s test, significant between-group differences were revealed (ANOVA: $F(3,590) = 8.84$; $p < 0.001$). Tukey’s post-hoc comparisons revealed higher values in younger groups compared to adolescents and adults. Linear regression showed that anxiety was most strongly associated with the severity of socioemotional limitations ($\beta = 0.636$; $p < 0.001$) with an independent negative effect of age ($\beta \approx -0.24$; $p < 0.01$). The model explained 44.4 % of the variance ($R^2 = 0.444$); VIF < 1.1. Psychometric analysis confirmed the two-factor structure with high internal consistency of the subscales ($\alpha = 0.904$ and $\alpha = 0.874$).

Conclusions. The quality of life of children and adolescents with celiac disease on a gluten-free diet is characterized by moderate "restriction burden" and associated anxiety. Anxiety is higher in younger age groups; no gender differences were found. The priority of medical and social support is to reduce daily limitations through organizational and environmental measures (in educational and leisure contexts, when eating out), supplemented by psychoeducational support for families, especially in younger age groups. According to the study, such measures are associated with reduced anxiety and improved daily functioning.

Keywords: children, adolescents, celiac disease, gluten-free diet, quality of life

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Качество жизни детей и подростков с целиакией в Российской Федерации: результаты поперечного мультицентрового исследования

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Введение. Изучение качества жизни пациентов, страдающих различными хроническими заболеваниями, включая целиакию, является важной составляющей научных исследований, определяя смысл и эффективность лечебных и реабилитационных стратегий. Оценке качества жизни детей с целиакией, находящихся на безглютеновой диете, посвящено незначительное число исследований. Кроме того, все они проведены с использованием различных опросников.
Цель: изучить качество жизни детей и подростков с целиакией, находящихся на безглютеновой диете, с помощью валидированной русскоязычной версии опросника CD-QOL.
Материалы и методы. В поперечном исследовании опрошены 599 детей и подростков с целиакией (возраст — 2–22 года) с использованием валидированной русскоязычной версии опросника CD-QOL; также оценивали влияние диеты на социальное функционирование. Сравнения проводили с помощью t-критерия Стьюдента (при нарушении однородности дисперсий — вариант Уэлча). Для возрастных групп использовали однофакторный дисперсионный анализ (ANOVA) с предварительной проверкой однородности дисперсий тестом Левена; при однородности выполнялся пост-хок тест Тьюки. В случаях отклонения от нормальности использовали непараметрический критерий Манна — Уитни для сравнения независимых групп. Для оценки влияния факторов на уровни показателей применяли множественную линейную регрессию; ассоциации между переменными дополнительно оценивали с помощью корреляции Пирсона или Спирмена. Уровень значимости — $p < 0{,}05$.
Результаты. Средние значения по субшкалам у 599 респондентов: «социально-эмоциональные ограничения» — 3,39 (SD = 0,96), «тревожность / страх за здоровье» — 3,16 (SD = 1,07). Между субшкалами обнаружена умеренно сильная положительная корреляция ($r = 0{,}649$; $p < 0{,}001$). Половых различий не обнаружено ($p = 0{,}956$ и $p = 0{,}970$ для обеих субшкал). В анализе по возрастным группам по компоненте «ограничения» наблюдалась статистическая тенденция (ANOVA: $F(3{,}590) = 2{,}63$; $p = 0{,}053$). Для компоненты «тревожность», при подтвержденной однородности дисперсий по тесту Левена, выявлены значимые межгрупповые различия (ANOVA: $F(3{,}590) = 8{,}84$; $p < 0{,}001$). Пост-хок сравнения по Тьюки показали более высокие значения у младших групп по сравнению с подростками и взрослыми. Линейная регрессия показала, что тревожность в наибольшей степени связана с выраженностью социально-эмоциональных ограничений ($\beta = 0{,}636$; $p < 0{,}001$) при независимом отрицательном эффекте возраста ($\beta \approx -0{,}24$; $p < 0{,}01$). Модель объясняет 44,4 % дисперсии ($R^2 = 0{,}444$); VIF < 1,1. Психометрический анализ подтвердил двухфакторную структуру с высокой внутренней согласованностью субшкал ($\alpha = 0{,}904$ и $\alpha = 0{,}874$).
Выводы. Качество жизни детей и подростков с целиакией на безглютеновой диете характеризуется умеренной «нагрузкой ограничений» и связанной с ней тревожностью. Тревожность выше в младших возрастных группах, половых различий не выявлено. Приоритет медико-социального сопровождения — снижение повседневных ограничений за счет организационных и средовых мер (в образовательных и досуговых контекстах, при питании вне дома), дополненных психообразовательной поддержкой семей, особенно в младших возрастных группах. Такие меры, по данным исследования, связаны со снижением тревожности и улучшением повседневного функционирования.
Ключевые слова: дети, подростки, целиакия, безглютеновая диета, качество жизни
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Introduction

The main goal of scientific research in medicine and clinical practice is to create strategies aimed both at a patient's complete recovery and at achieving stable remission. Along with traditional biomedical indicators, the assessment of a patient's quality of life (QoL), as one of the indicators of treatment and rehabilitation effectiveness, is becoming increasingly relevant. QoL assessment is becoming one of the key criteria reflecting the effectiveness of treatment plans for individual patients and their condition monitoring [1, 2]. In this context, studying QoL in celiac disease is of great scientific interest, as celiac disease represents not only a medical but also a socially significant problem due to its high prevalence [3–6]. It is caused by several factors, including:

– lack of information on the true prevalence of celiac disease, considering its often asymptomatic or mildly symptomatic course [7–9],

– difficulties adhering to a gluten-free diet, caused both by the patient's personality traits and by the attitudes of their relatives and acquaintances towards the restrictive nature of the diet [10, 11],

– difficulties in making correct choices of gluten-free products [12, 13].

Aim of the study: to investigate the quality of life in children with celiac disease using the validated CD-QOL questionnaire.

Materials and methods

This study was based on the results of an online questionnaire for assessment of the quality of life in children and adolescents with celiac disease. The tool included 20 statements rated on a five-point Likert scale (1–5), and was structured into two content subscales: “socio-emotional restrictions” and “anxiety/health-related fear”. The full list of statements is presented below for the tool's reproducibility (Table 1).

The analysis included valid responses from 599 respondents (parents/legal representatives). Questionnaires containing no indication of the child's age were included in analyses that did not require age stratification (descriptive statistics, aggregated score assessment and subscale correlation) but were excluded from procedures where age was a factor (intergroup comparisons by age, regression models). Missing data were handled by listwise deletion at each analysis level. Questionnaires with missing data in key subscale items were not considered when calculating the respective aggregated scores.

A confirmed diagnosis of celiac disease in a child based on the recommendations of the ESPGHAN was the main inclusion criterion. The sample's demographic structure included stratification into four age groups (0–6, 7–12, 13–17, 18+ years) with adjustment for sex at all stages of intergroup comparisons (Table 2).

Preliminary checks did not reveal statistically significant sex differences by composite scales, confirming subgroup comparability by sex for subsequent analysis; the robustness of this finding was verified using a set of alternative tests (Welch's *t*-test for independent samples, non-parametric Mann — Whitney *U* test) under the assumption of homogeneity of variances (Levene's test), and the calculated effect sizes (Cohen's d) corresponded to small values. For the sake of methodological rigor, sensitive analysis was additionally carried out including sex as a covariate in the models, which did not change direction or significance of the main assessments. Thus, unification of male and female subgroups for the calculation of aggregated scores is considered statistically justified; however, sex was retained as a covariate at the stage of intergroup comparisons and regression analyses.

Methods of statistical processing

Statistical processing was carried sequentially and included: univariate analysis (absolute and relative frequencies for each item and aggregated scores for subscales); intergroup comparisons by sex (Student's *t*-test for independent samples with robustness checks using Welch's *t*-test and Mann — Whitney test) and by age groups (one-way analysis of variance (ANOVA), including Levene's test for homogeneity of variances and *post-hoc* pairwise comparisons using Tukey's test, if homogeneity is met; if violated, then using the Games — Howell procedure). Aggregated scores for subscales were calculated as the mean values of the items of the corresponding subscale; correlations and regression models were constructed based on aggregated subscale scores. Pearson/Spearman correlations and linear regression were used to assess relationships (“anxiety/health-related fear” being a dependent variable; “socio-emotional restrictions” and age being predictors); the Pearson correlation coefficient was used when assumptions of approximate normality of distributions and linearity of the relationship were met, and when these assumptions were violated, the Spearman coefficient was applied. The psychometric suitability of the tool was confirmed by exploratory factor analysis using the principal component method with varimax rotation (the Kaiser — Meyer — Olkin (KMO) test was assessed) and by the Bartlett's test. The two-component structure is reproduced: the items of “socio-emotional restrictions” load on Component 1, while the items of “anxiety/health-related fear” load on Component 2 (Table 3).

The threshold for significant loadings is set at 0.40; higher scores on items reflect higher severity of distress. Factor selection was based on eigenvalue criterion $\lambda > 1$ and the scree plot; internal consistency – on Cronbach's α coefficient; the suitability for factorization was confirmed (KMO exceeded the minimal acceptable threshold, Bartlett's test was significant), internal consistency of the subscales was assessed using Cronbach's α.

Table 1. Questionnaire for research into quality of life in celiac disease

Section 1. General information about the respondent	
1. The child's age (in years): *(open answer)*	
2. The child's sex:	a. male b. female
3. Please indicate the district/region where you live: *(open answer)*	
Section 2	
1. I feel restrictions due to the disease.	a. Not at all b. A little c. Moderately d. Strongly e. Very strongly
2. I feel anxious that I will be suffering from this disease.	a. Not at all b. A little c. Moderately d. Strongly e. Very strongly
3. I feel anxious that my disease can cause other health-related problems.	a. Not at all b. A little c. Moderately d. Strongly e. Very strongly
4. I feel anxious that my disease can increase the risk of developing cancer.	a. Not at all b. A little c. Moderately d. Strongly e. Very strongly
5. I feel that society condemns me due to the disease.	a. Not at all b. Slightly c. Moderately d. It worries me e. I am absolutely sure it matters
6. I feel restricted from sharing meals with friends and classmates.	a. Not at all b. Slightly c. Moderately d. It worries me e. I am absolutely sure it matters
7. I feel that I cannot eat certain foods, for example pizza or cake.	a. Not at all b. A little c. Moderately d. Strongly e. Very strongly
8. I feel that adhering to the diet is not enough for treating my disease.	a. Not at all b. A little c. Moderately d. Strongly e. Very strongly
9. I feel that there are few treatment options available to me.	a. Not at all b. A little c. Moderately d. Strongly e. Very strongly
10. I feel depressed due to the disease.	a. Not at all b. A little c. Moderately d. Strongly e. Very strongly

End of Table 1. Questionnaire for research into quality of life in celiac disease

11. I feel frightened due to the disease.	a. Not at all b. A little c. Moderately d. Strongly e. Very strongly
12. I feel that I do not know enough about my disease.	a. Not at all b. A little c. Moderately d. Strongly e. Very strongly
13. I feel overwhelmed due to the disease.	a. Not at all b. A little c. Moderately d. Strongly e. Very strongly
14. I feel difficulty communicating due to the disease.	a. Not at all b. A little c. Moderately d. Strongly e. Very strongly
15. I have difficulty travelling or on long trips.	a. Not at all b. A little c. Moderately d. Strongly e. Very strongly
16. I feel that I cannot live a normal life due to the disease.	a. Not at all b. A little c. Moderately d. Strongly e. Very strongly
17. I am nervous about eating out because the food might contain gluten.	a. Not at all b. A little c. Moderately d. Strongly e. Very strongly
18. I am worried that some family member might develop celiac disease.	a. Not at all b. A little c. Moderately d. Strongly e. Very strongly
19. I feel that I am always thinking about food.	a. Not at all b. A little c. Moderately d. Strongly e. Very strongly
20. I am worried that the disease will affect me in the future.	a. Not at all b. A little c. Moderately d. Strongly e. Very strongly

Table 2. Demographic structure of the sample ($n = 599$)

The child’s sex	Age group	Number	% of total number
Female	0–6	82	13.8
	7–12	154	25.9
	13–17	64	10.8
	18+	29	4.9
Male	0-6	69	11.6
	7-12	144	24.2
	13-17	41	6.9
		11	1.9

Table 3. Correspondence of questionnaire items to subscales and factor loadings (the method of principal components; varimax rotation)

Item formulation	Subscale	Loading on component
6. I feel restricted from sharing meals with friends and classmates.	Socio-emotional restrictions	0.791
16. I feel that I cannot live a normal life due to the disease.	Socio-emotional restrictions	0.768
7. I feel that I cannot eat certain foods, for example pizza or cake.	Socio-emotional restrictions	0.757
1. I feel restrictions due to the disease.	Socio-emotional restrictions	0.704
10. I feel depressed due to the disease.	Socio-emotional restrictions	0.698
13. I feel overwhelmed due to the disease.	Socio-emotional restrictions	0.670
14. I feel difficulty communicating due to the disease.	Socio-emotional restrictions	0.641
15. I have difficulty travelling or on long trips.	Socio-emotional restrictions	0.628
2. I feel anxious that I will be suffering from this disease.	Socio-emotional restrictions	0.586
5. I feel that society condemns me due to the disease.	Socio-emotional restrictions	0.570
4. I feel anxious that my disease can increase the risk of developing cancer.	Anxiety/health-related fear	0.827
3. I feel anxious that my disease can cause other health-related problems.	Anxiety/health-related fear	0.802
20. I am worried that the disease will affect me in the future.	Anxiety/health-related fear	0.795
11. I feel frightened due to the disease.	Anxiety/health-related fear	0.698
18. I am worried that some family member might develop celiac disease.	Anxiety/health-related fear	0.670
12. I feel that I do not know enough about my disease.	Anxiety/health-related fear	0.616

The threshold for statistical significance was set at $p < 0.05$.

Results and discussion

Quality of life profile and inter-component relationships

In total, the responses of 599 respondents showed a moderate expression of both components of quality of life: the mean value for the “socio-emotional restrictions” component was 3.39 (SD = 0.96), and for the “anxiety/health-related fear” component it was 3.16 (SD = 1.07) (scales 1–5). A higher variance in anxiety indicates greater intragroup heterogeneity of experiences. A moderately strong positive relationship between the components was revealed ($r = 0.649$; $p < 0.001$), reflecting the interconnected nature of emotional-behavioral constraints and anxious expectations: the increasing subjective “burden of restrictions” is associated with rising anxiety.

The obtained profile (moderate means with noticeable variation of anxiety) indicates that the burden for families living with celiac disease is not homogeneous: some respondents demonstrate adaptive trajectories, while others retain pronounced concerns. A moderately strong association between restrictions and anxiety supports the notion of a bidirectional connection: organisational and environmental barriers (eating out, communication, planning) are linked to growing anxious expectations, while increased anxiety is associated with a more intense experience of restrictions.

It is advisable to implement systematic anxiety assessment alongside daily restrictions monitoring, and to progressively develop educational modules focused on planning meals and social interaction, as well as environmental conditions reducing barriers at schools and public spaces. At the time of resource allocation, priority should be given to groups with a high “burden of restrictions” and pronounced anxiety, as these are expected to experience the greatest improvement in quality of life.

Age-sex profile of quality-of-life indicators

Age differences for the "socio-emotional restrictions" component showed a statistical trend: $F(3.590) = 2.63$; $p = 0.053$; marked differences between groups were observed for the "anxiety/health-related fear" component: $F(3.590) = 8.84$; $p < 0.001$ (one-way analysis of variance). Homogeneity of variances by Levene's test was not rejected ($p = 0.178$ and $p = 0.804$); the classic version of ANOVA and Tukey's post hoc test were used. Post hoc comparisons using Tukey's test showed higher anxiety scores in younger groups (0–6; 7–12 years) compared to adolescents (13–17 years) and adults (18+ years).

The observed age gradient in anxiety, coinciding with relative stability in restrictions, is consistent with the developmental progression of self-regulation and accumulation of daily living skills in adolescents and adults. Apparently, higher anxiety levels in younger people reflect a limited range of coping strategies and greater uncertainty in typical social situations (preschool institutions/elementary school), as well as the families' reliance on external infrastructure (accessibility to safe gluten-free options, awareness of surrounding people about celiac disease). The absence of sex differences may be interpreted as a sign of dominance of universal environmental factors over potential sex-specific variations in affective responses.

In spite of the small value of the "age-anxiety" correlation ($r \approx 0.14$), clinical significance persists, since even a moderate distribution bias in the 0–12 age groups results in an increased proportion of families in need of targeted support. In practice, this justifies focusing educational and training modules on younger age groups (such as planning eating out, communication scenarios, and self-regulation techniques), alongside the simultaneous development of system-wide organisational solutions for all ages (including standardisation of school and recreation practices, allergy safety labelling, dietary guidelines, and personnel training) and reducing the logistical burden on families.

Key predictors of anxiety

A linear regression model with "anxiety/health-related fear" as the dependent variable and "socio-emotional restrictions" and "age" as predictors is statistically significant and explains 44.4 % of the variance ($R^2 = 0.444$; $p < 0.001$). The severity of socio-emotional restrictions acts as the leading predictor ($\beta = 0.636$; $p < 0.001$). Age introduces an independent negative impact ($\beta \approx -0.24$; $p < 0.01$) with a low multicollinearity (variance inflation factor (VIF) < 1.1). Sensitivity analysis showed that alternative model specifications (adding sex as a covariate; coding age by groups/continuously) do not change the direction of effects. Fluctuations in the age estimate β (up to ≈ -0.50) reflect differences in parameterisation.

The predominant role of socio-emotional restrictions indicates their status as the proximal determinant of anxiety: the greater the subjective "burden of restrictions" (including the complexity of daily activities, eating out, engagement in communication, and participation in events), the higher the affective tension related to health. A negative connection with age aligns with the accumulation of self-regulation skills and environmental controllability in adolescents and adults (better planning, greater experience in navigating gluten-free options), which shifts anxiety levels downwards, without eliminating the underlying source of restrictions. In other words, age predominantly modifies the severity of anxiety, whereas the restrictions profile is primarily determined by organisational and environmental conditions.

The greatest expected anxiety-reducing effect is associated with alleviating the "burden of restrictions" through organisational changes in the environment and training families in daily navigation skills. Age must be considered a modifying risk factor (it is higher in younger individuals); however, the primary focus remains on socio-emotional restrictions.

Risk matrix and the priorities for organising medical and social support

Risk stratification relies on the convergence of three blocks of results: (i) socio-emotional restrictions are the leading predictor of anxiety (having the greatest standardised impact), (ii) age is an independent negative predictor (with greater anxiety seen in younger groups), (iii) no significant differences by sex were noted in integral assessments. Hence, the priority focus of support must be given to reducing the "burden of restrictions" through organisational and environmental solutions in places where children and their families spend time daily: predictability of procedures, clear routing of follow-up, accessibility of safe food outside their homes, and informing families and learning communities.

In order to set up the process of organising support, it is advisable to use risk stratification matrix 2 × 2 based on two indicators (anxiety × restrictions), which enables targeted planning of support measures. Combined solutions are appropriate for a cluster characterised by high anxiety and high limitations (support in navigating available resources, organisational adjustments to the environment, educational modules on planning and communication). In clusters where one component is predominant, the focus shifts accordingly: either to improving environmental conditions and availability of options or to developing self-regulation and social interaction skills. It is appropriate to consider both indicators as sensitive markers of support dynamics, with an expected cascade of associations: a reduction in restrictions is associated with a reduction in anxiety and an improvement of daily functioning.

At the system level, priority is given to organisational conditions that do not intrude on the family's personal space: standardisation of school and recreational practices (allergy safety labelling, dietary guidelines, personnel training), increased availability of "gluten-free" infrastructure in public places and food service organisations, as well as navigation tools for families (check lists, "quick food kits", targeted reference books). Age should be taken into consideration as a modifying factor: psycho-educational components are appropriate for younger groups (0–12 years) as part of follow-up pathways.

The optimal focus is on developing environmental conditions and organisational processes that reduce the "burden of restrictions", along with simultaneous use of unobtrusive educational modules for younger age groups. Such approach supports family autonomy and allows directing resources to where the greatest improvement in quality of life is expected.

Limitations and applicability of results

The study was performed in an online format and is based on data provided by parents / legal representatives, which entails the risks of selection and information bias (voluntary participation, uneven access to digital channels, perceptual distortions when assessing anxiety and restrictions). A cross-sectional design captures associations at a single time point and does not allow for cause-and-effect conclusions; it is also affected by unaccounted covariates (such as socio-economic status, regional differences in infrastructure, length of the disease / diet) and residual confounding, despite low multicollinearity in the models. Varying density of age strata and potential non-homogeneity of environmental conditions (schools, regions, accessibility of "gluten-free" options) act as additional sources of variability.

At the same time, the consistency of results between parametric and non-parametric procedures, reproducibility of the direction of effects in intergroup and correlation analyses, as well as confirmed psychometric suitability of the two-subscale model, support the reliability of the basic conclusions and their applied use in medical and social support services (including monitoring dynamics using two indicators).

In order to increase generalisability and confirm the expected dynamics, longitudinal observations are advisable, including objective markers and independent data sources: clinical and laboratory indicators and markers of diet adherence, audit of school/organisational protocols and availability of options, registration/service data on resource usage. Mixed methods (quantitative data and qualitative interviews) are promising, as is extended stratification by socio-demographic characteristics, which will allow clarification of the generalisability of results to different contexts and identification of groups where the greatest improvement in quality of life is expected.

Conclusion

A cross-sectional study of quality of life in 599 children and adolescents with celiac disease following a gluten-free diet found moderate levels of "social-emotional limitations" and "health anxiety / worry" with significant variability between participants. A moderately strong relationship was found between the subscales; the main statistical predictor of anxiety was subjectively perceived "burden of restrictions", while age had an independent negative modifying effect. No gender differences were found.

This indicates that the burden associated with the disease is mainly formed by organizational and environmental barriers of everyday life (eating outside the home, participation in educational and leisure activities, communication). Age differences likely reflect the accumulation of self-regulation skills and the ability to navigate a gluten-free environment. Therefore, the priority in medical and social support is to reduce daily restrictions through standardization and adaptation of environmental conditions; such changes are associated with reduced anxiety and improved daily functioning.

Practical recommendations should be implemented in two areas:

1. Developing a daily environment based on gluten-free principles in educational and leisure contexts: regulations and labeling, adapted menus, staff training, and proven communication algorithms; expanding accessible, safe food options; and creating short navigation tools for families.
2. Strengthening psychoeducational support for children and their families, especially those aged 0–12: planning meals outside the home, practicing interaction scenarios, and basic self-regulation techniques.

Both approaches reduce the anxiety factor associated with the "burden of daily restrictions", which together will lead to a reduction in affective tension and an improvement in everyday functioning.

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