

The quality of life in developing age children with celiac disease

T. DI FILIPPO¹, M. F. ORLANDO², G. CONCIALDI², S. LA GRUTTA³, R. LO BAIDO⁴
M. S. EPIFANIO³, M. ESPOSITO⁵, M. CAROTENUTO⁵, L. PARISI⁶, M. ROCCELLA⁶

Aim. The moments that follow the diagnosis of celiac disease and the early stages of the gluten-free diet are extremely difficult and complex for parents and child, because they face an important change punctuated by self-denial and deprivation. The main objective of this research is to assess the impact of celiac disease on quality of life in subjects in developmental age, taking into account the perceptions of parents about the child's illness, with the aim to highlight the effect of disease on the child and the entire family.

Methods. The study included both parents of 45 children aged between 2 and 10 years, with established celiac disease. To evaluate the effect of celiac disease on the lifestyle of affected children and their families has been used, after having adapted to the Italian context, the Impact Scale of Childhood Diseases of Hoare and Russell (1995). This study shows that celiac disease is a condition that has a significant impact on both the child and his family.

Results and conclusion. The results obtained by administration of Impact Scale of Childhood Diseases to parents showed that subjects in developmental age with celiac disease could have difficulty on emotional level that affect child development and the whole family context. Acceptance of the illness by the child depends mainly by how much and how this has been accepted by parents.

KEY WORDS: Celiac disease - Quality of life - Child.

Celiac disease is characterized as a chronic condition, the care of which is

Corresponding author: T. Di Filippo, Via Felice Cavallotti 9/A, 90123 Palermo, Italy. E-mail: terry_1982@libero.it

¹Unit of Story of Culture and Technique
Department of Psychology
University of Palermo, Palermo, Italy

²Faculty of Psychology
Unit of Palermo, Palermo Italy

³Unit of Clinical Psychology
Department of Psychology
University of Palermo, Palermo, Italy

⁴Department of Clinical Psychiatry
University of Palermo, Palermo, Italy

⁵Clinic of Child and Adolescent Neuropsychiatry
Second University of Naples, Naples, Italy

⁶Unit of Child Neuropsychiatry
Department of Psychology
University of Palermo, Palermo, Italy

represented by a gluten-free diet. In celiac disease the respect of a strict gluten-free diet allows the disappearance of physical symptoms, but at the same time, involves a total change of lifestyle, and brings into play all the issues related to the acceptance, to the compliance, and to the subjective perception of quality of life.¹

Celiac disease has a strong impact on the development of children, both in terms of their physical health and in the emotional, behavioral and social.²

The diagnosis in childhood, especially during the first two years, it seems to be a psychologically protective factor: the child grows up in a world without gluten, and the diet seems to be more easily integrated in a lifestyle future.¹⁻³ Instead, a diagnosis later

school age (8-10 years) would seem to be more traumatic, and accompanied by specific behavioral emotional reactions such as irritability, listlessness in school, aggression with peers. At the time of the comparison in terms of social relationships, in the child could born the conviction to be different because of the inability to share important aspects of "life group" with their peers, such as food, interferes with his need to receive confirmations and to be integrated to the group, psychologically important for the growth and identity formation.⁴

The moments that follow the diagnosis of celiac disease and the early stages of the gluten-free diet are extremely difficult and complex for parents and child, because they face an important change punctuated by self-denial and deprivation.⁵

Acceptance of the illness by the child depends mostly on how the family reacts to change.⁶⁻⁷

Like any event that stresses the system, celiac disease reveals the nature of the family, which has to try the resources to find a new balance, on times and in ways that will be more appropriate to improve the quality of life of their child.⁸

A family that manages to overcome the initial psychological distress and flexibly changes their habits, will allow to the celiac child to establish in a more serene way a compliance to the diet, and help him to gain independence and responsibility for its condition.⁹ The main objective of this research is to assess the impact of celiac disease on quality of life in subjects in developmental age in terms of the physical, psychological and social, taking into account the perceptions of parents about the child's illness, with the aim to highlight the effect of disease on the child and the entire family.

Materials and methods

The study included both parents of 45 children aged between 2 and 10 years, with established celiac disease. The families were recruited through the Department of Pediatric Gastroenterology of the G. Cristina Hos-

pital of Palermo, and from the Italian Celiac Association (AIC) of Palermo and Trapani. Specifically, the study referred to 29 female pediatric patients (64.4%) and 16 male (35.6%) with a mean age of 6.4 years, 22 (48.9%) with classical or typical celiac disease, 23 (51.1%) with atypical celiac disease.

As for parents, mothers had an average age of 37 years and the fathers of 41.6 years. The majority of them had the higher degree (43.3%), followed by the middle school (30%), the graduation (24.5%), and finally the elementary school (2.2%).

To evaluate the effect of celiac disease on the lifestyle of affected children and their families has been used, after having adapted to the Italian context, the Impact Scale of Childhood Diseases of Hoare and Russell (1995) (Table I). This is a questionnaire constructed in order to obtain an assessment of quality of life in children with epilepsy and other chronic illnesses and in their families. All questions in the questionnaire related to the effect that the disease has on the child, the parents and the family.

The scale is composed by 30 questions divided into 4 sections: impact of illness and its treatment (questions 1/5); impact on child's development and adjustment (questions 6/15); impact on parents (16/20 questions), and impact on the family (question 21/30).

For each question, the parent had to give an answer in 2 dimensions: frequency and importance. The first referred to how often arose a particular problem or situation, and the second to quantity of concern it produced. The 2 variables for each question were scored 0, 1 or 2. The questionnaire, also contains a brief preliminary section that explains to parents the aim of the assessment procedure. Statistical correlation and descriptive analysis were used for data elaboration.

The administration of the questionnaire was preceded by an anamnestic interview with the parents. Through the interview were investigated different areas: the first part of the interview referred to information about age of the child, age of parents, their qualifications and their profession, and the

TABLE I.—Number of the cases and percentage of mothers' answers on "frequency" parameter

Questions	Answers					
	Never or rarely		Sometimes		Often	
	N.	%	N.	%	N.	%
1 Can my child stop breathing because of his illness?	44	97.8	-	-	1	2.2
2 Is there a risk he/she may injure himself/herself?	27	60.0	11	24.4	7	15.6
3 Is there a risk he/she may suffer brain damage or die?	35	77.8	8	17.8	2	4.4
4 Do drugs my child takes makes him/her less alert?	45	100.0	-	-	-	-
5 Do drugs worse his/her behavior?	45	100.0	-	-	-	-
6 Is my child more moody because of his/her illness?	29	64.4	14	31.2	2	4.4
7 Is He/she shy and more easily embarrassed?	24	53.4	19	42.2	2	4.4
8 Is my child teased and bullied because of his/her illness?	34	75.6	10	22.2	1	2.2
9 Has he/she few friends because of his/her illness?	43	95.6	-	-	2	4.4
10 Has he/she few interests because of his/her illness?	44	97.8	1	2.2	-	-
11 Has my child problems in reading or maths because of his/her illness?	43	95.6	2	4.4	-	-
12 Is my child less clever because of his/her illness?	45	100.0	-	-	-	-
13 Can my child find a job when he/she leaves school?	44	97.8	1	2.2	-	-
14 Could my child have to take drugs for years?	42	93.4	2	4.4	1	2.2
15 Could my child not marry or have a family?	43	95.6	2	4.4	-	-
16 Does my child makes a fuss about taking his/her drugs?	40	88.9	4	8.8	1	2.2
17 Is it difficult for him/her to use public transports because of his/her illness?	45	100.0	-	-	-	-
18 Is he/she less able to care for him/herself?	42	93.4	3	6.6	-	-
19 Is it difficult to explain my child's illness to others?	21	46.7	21	46.7	3	6.6
20 Is it difficult to explain my child his/her own illness?	33	73.4	11	24.4	1	2.2
21 Must my child be more closely watched than other children because of his/her illness?	13	28.9	28	62.3	4	8.8
22 Is it difficult to give my other children enough attention?	38	84.4	6	13.4	1	2.2
23 Does my child's illness limit what his/her brothers and sisters can do?	39	86.6	6	13.4	-	-
24 Must we limit our holidays?	19	42.2	25	55.6	1	2.2
25 Have we fewer friends around because of his/her illness?	43	95.6	2	4.4	-	-
26 Does my child's illness limit when we go out as family?	29	64.4	14	31.2	2	4.4
27 Have we more arguments at home?	41	91.2	4	8.8	-	-
28 Do we go out less often in the evenings as a couple?	32	71.2	10	22.2	3	6.6
29 Is my son more difficult to manage because his/her illness?	30	66.6	14	31.2	1	2.2
30 Must we refuse job's opportunities because of his/her illness?	42	93.4	2	4.4	1	2.2

possible presence of other diseases in family in addition to celiac disease. The second part was about to pregnancy, childbirth, neonatal adaptation and possible presence of neurological disorders in children. The interview proceeded investigating the perception that parents have of the celiac disease, the emotional experience of the child, the age of diagnosis, how was discovered the disease and how it was explained to the child, the mood expressed by the child before and after diagnosis, the possible need by the couple to receive the psychological therapy for the child.

Finally, we investigated the area on the level of information about celiac disease of parents, the limitations that disease im-

poses, especially outside the family context, and the perception which parents had compared to the change in quality of life of the child with the introduction of gluten-free diets.

The study was approved by the committee on research ethics at the institution in which the research was conducted and any informed consent from human subjects was obtained as required.

Results

Analysis of frequencies and percentages of responses (Tables I-IV) showed that the

TABLE II.—*Number of the cases and percentage of mothers' answers on "importance" parameter*

Questions	Answers					
	Not much concern		Some concern		A lot of concern	
	N.	%	N.	%	N.	%
1 Can my child stop breathing because of his illness?	2	4.4	4	8.8	39	86.6
2 Is there a risk he/she may injure himself/herself?	2	4.4	14	31.2	29	64.4
3 Is there a risk he/she may suffer brain damage or die?	2	4.4	14	31.2	29	64.4
4 Do drugs my child takes makes him/her less alert?	1	2.2	1	2.2	43	95.6
5 Do drugs worse his/her behavior?	1	2.2	-	-	44	97.8
6 Is my child more moody because of his/her illness?	-	-	14	31.2	31	68.8
7 Is He/she shy and more easily embarrassed?	1	2.2	15	33.4	29	64.4
8 Is my child teased and bullied because of his/her illness?	1	2.2	14	31.2	30	66.6
9 Has he/she few friends because of his/her illness?	3	6.6	3	6.6	39	86.6
10 Has he/she few interests because of his/her illness?	-	-	1	2.2	44	97.8
11 Has my child problems in reading or maths because of his/her illness?	-	-	3	6.6	42	93.4
12 Is my child less clever because of his/her illness?	-	-	-	-	45	100.0
13 Can my child find a job when he/she leaves school?	-	-	-	-	45	100.0
14 Could my child have to take drugs for years?	-	-	4	8.8	41	91.2
15 Could my child not marry or have a family?	-	-	2	4.4	43	95.6
16 Does my child makes a fuss about taking his/her drugs?	1	2.2	7	15.6	37	82.2
17 Is it difficult for him/her to use public transports because of his/her illness?	-	-	-	-	45	100.0
18 Is he/she less able to care for him/herself?	-	-	8	17.8	37	82.2
19 Is it difficult to explain my child's illness to others?	5	11.1	19	42.2	21	46.7
20 Is it difficult to explain my child his/her own illness?	5	11.1	13	28.9	27	60.0
21 Must my child be more closely watched than other children because of his/her illness?	7	15.6	27	60.0	11	24.4
22 Is it difficult to give my other children enough attention?	1	2.2	6	13.4	38	84.4
23 Does my child's illness limit what his/her brothers and sisters can do?	2	4.4	7	15.6	36	80.0
24 Must we limit our holidays?	19	42.2	22	49.0	19	42.2
25 Have we fewer friends around because of his/her illness?	-	-	4	8.8	41	91.2
26 Does my child's illness limit when we go out as family?	2	4.4	17	37.8	26	57.8
27 Have we more arguments at home?	-	-	3	6.6	42	93.4
28 Do we go out less often in the evenings as a couple?	1	2.2	12	26.6	32	71.2
29 Is my son more difficult to manage because his/her illness?	2	4.4	12	26.6	32	71.2
30 Must we refuse job's opportunities because of his/her illness?	1	2.2	4	8.8	40	88.9

most common problems associated with celiac disease, for both parents (who have answered "sometimes" or "often" in the frequency parameter, and "some concern" or "a lot of concern" about the importance parameter) were mainly: the child's behavior and mood, the problems in explaining the disease to others, the supervision, the limits that celiac disease creates in the extrafamilial context.

An interesting point to highlight concerns some questions that according to the frequency parameter showed relatively low percentages, while the importance parameter revealed higher rates. Specifically these are the questions on the risk that child in-

jure himself (question 2), and the risk that he may suffer brain damage or die (question 3). These questions showed concerns towards those situations for their children for both parents but at the same time did not consider them as complications of celiac disease. Some parents expressed a concern especially towards the possible diseases associated with celiac disease, autoimmune diseases, epilepsy and autism.

Another interesting fact is that there were for both parents, high percentages in the responses "sometimes" and "some concern" in the questions 19, 21, 24 and 26.

In question 19 many couples said they face difficulties in explaining to others what

TABLE III.—*Number of the cases and percentage of fathers' answers on "frequency" parameter*

Questions	Answers					
	Never or rarely		Sometimes		Often	
	N.	%	N.	%	N.	%
1 Can my child stop breathing because of his illness?	44	97.8	-	-	1	2.2
2 Is there a risk he/she may injure himself/herself?	36	80.0	8	17.8	1	2.2
3 Is there a risk he/she may suffer brain damage or die?	38	84.4	4	8.8	3	6.6
4 Do drugs my child takes makes him/her less alert?	45	100.0	-	-	-	-
5 Do drugs worse his/her behavior?	45	100.0	-	-	-	-
6 Is my child more moody because of his/her illness?	33	73.4	10	22.2	2	4.4
7 Is He/she shy and more easily embarrassed?	28	62.2	17	37.8	-	-
8 Is my child teased and bullied because of his/her illness?	39	86.6	6	13.4	-	-
9 Has he/she few friends because of his/her illness?	44	97.8	-	-	1	2.2
10 Has he/she few interests because of his/her illness?	44	97.8	1	2.2	-	-
11 Has my child problems in reading or maths because of his/her illness?	42	93.4	3	6.6	-	-
12 Is my child less clever because of his/her illness?	44	97.8	1	2.2	-	-
13 Can my child find a job when he/she leaves school?	43	95.6	1	2.2	1	2.2
14 Could my child have to take drugs for years?	45	100.0	-	-	-	-
15 Could my child not marry or have a family?	45	100.0	-	-	-	-
16 Does my child makes a fuss about taking his/her drugs?	36	80.0	9	20.0	-	-
17 Is it difficult for him/her to use public transports because of his/her illness?	45	100.0	-	-	-	-
18 Is he/she less able to care for him/herself?	39	86.6	5	11.1	1	2.2
19 Is it difficult to explain my child's illness to others?	18	40.0	21	46.7	6	13.4
20 Is it difficult to explain my child his/her own illness?	32	71.2	13	28.9	-	-
21 Must my child be more closely watched than other children because of his/her illness?	21	46.7	18	40.0	6	13.4
22 Is it difficult to give my other children enough attention?	42	93.4	2	4.4	1	2.2
23 Does my child's illness limit what his/her brothers and sisters can do?	35	77.8	10	22.2	-	-
24 Must we limit our holidays?	24	53.3	19	42.2	-	-
25 Have we fewer friends around because of his/her illness?	42	93.4	3	6.6	-	-
26 Does my child's illness limit when we go out as family?	30	66.6	13	28.9	2	4.4
27 Have we more arguments at home?	43	95.6	2	4.4	-	-
28 Do we go out less often in the evenings as a couple?	31	68.8	13	28.9	1	2.2
29 Is my son more difficult to manage because his/her illness?	32	71.2	12	26.6	1	2.2
30 Must we refuse job's opportunities because of his/her illness?	42	93.4	3	6.6	-	-

is celiac disease: «often people do not understand, there is much misinformation and unpreparedness about disease». So it becomes difficult to explain all that it entails, many precautions to use in the preparation of food for celiac, the aspect of contamination and the rigidity with which the diet must be followed.

Question 21 had particularly high rates of mothers (62.2% of respondents "sometimes" and 60% of respondents "some concern") which gave more attention to their celiac child respect other children, they worried that their child could eat food with gluten, and lived a state of alert when their child is away from home, away from their control

and with unfamiliar people (during holidays and school trips).

Answers to questions 24 and 26 showed the difficulties and concerns of parents when their child and the family have to go out or have a holiday. Parents sometimes said they felt worried, anxious but despite the practical problems that the disease creates, they tried to implement strategies aimed to render life easier outside the family context. This allows the possibility of a trip or simply participate in the festivities without limitation.

Particular importance was the question 6 on the child's bad mood because of the disease; the answers to this question changed

TABLE IV.—*Number of the cases and percentage of fathers' answers on "importance" parameter*

Questions	Answers					
	Not much concern		Some concern		A lot of concern	
	N.	%	N.	%	N.	%
1 Can my child stop breathing because of his illness?	2	4.4	5	11.1	38	84.4
2 Is there a risk he/she may injure himself/herself?	1	2.2	11	24.4	33	73.4
3 Is there a risk he/she may suffer brain damage or die?	1	2.2	7	15.6	37	82.2
4 Do drugs my child takes makes him/her less alert?	-	-	-	-	45	100.0
5 Do drugs worse his/her behavior?	-	-	-	-	45	100.0
6 Is my child more moody because of his/her illness?	2	4.4	12	26.6	31	68.8
7 Is He/she shy and more easily embarrassed?	2	4.4	15	28.9	30	66.6
8 Is my child teased and bullied because of his/her illness?	1	2.2	8	17.8	36	80.0
9 Has he/she few friends because of his/her illness?	-	-	4	8.8	41	91.2
10 Has he/she few interests because of his/her illness?	-	-	1	2.2	44	97.8
11 Has my child problems in reading or maths because of his/her illness?	-	-	4	8.8	41	91.2
12 Is my child less clever because of his/her illness?	1	2.2	1	2.2	43	95.6
13 Can my child find a job when he/she leaves school?	1	2.2	1	2.2	43	95.6
14 Could my child have to take drugs for years?	-	-	3	6.6	42	93.4
15 Could my child not marry or have a family?	-	-	-	-	45	100.0
16 Does my child makes a fuss about taking his/her drugs?	-	-	9	20.0	36	80.0
17 Is it difficult for him/her to use public transports because of his/her illness?	-	-	-	-	45	100.0
18 Is he/she less able to care for him/herself?	-	-	6	13.4	39	86.6
19 Is it difficult to explain my child's illness to others?	7	15.5	20	44.4	18	40.0
20 Is it difficult to explain my child his/her own illness?	1	2.2	13	28.9	31	58.8
21 Must my child be more closely watched than other children because of his/her illness?	8	17.8	18	40.0	19	42.2
22 Is it difficult to give my other children enough attention?	1	2.2	4	8.8	40	88.9
23 Does my child's illness limit what his/her brothers and sisters can do?	2	4.4	7	15.6	36	80.0
24 Must we limit our holidays?	4	8.8	16	35.6	25	55.6
25 Have we fewer friends around because of his/her illness?	-	-	2	4.4	43	95.6
26 Does my child's illness limit when we go out as family?	3	6.6	11	24.4	31	68.8
27 Have we more arguments at home?	1	2.2	5	11.1	39	86.6
28 Do we go out less often in the evenings as a couple?	1	2.2	8	17.8	36	80.0
29 Is my son more difficult to manage because his/her illness?	2	4.4	8	17.8	35	77.8
30 Must we refuse job's opportunities because of his/her illness?	1	2.2	2	4.4	42	93.4

according to age of diagnosis of the disease in children. Parents of children between 2 and 6 years, with early diagnosis have answered that in the period before diagnosis, the child was very sad, apathetic, nervous, as a reaction to the state of physical distress for six, eighteen months after diagnosis; the mood is much improved after a long period of diet, and for the early diagnosis the celiac disease has been fully accepted by the child and is accepted as part of his life. Parents of children aged between 7 and 10 years, said that sometimes they saw their son grumpy, irritable, sad though he followed the diet and he was healthy physically; it seems that this is due to the fact that the child begins

to establish his first social relationships, and comparing with peers, he is not always easy to explain because he ate differently and because he should always bring his food. All this may create in him some embarrassment, that over time, it could bring to avoid confrontation with others to not feel different and not be refused. The parents didn't show concerns and didn't think that their son was teased or ridiculed because of his illness, or that he had less interests or problems with reading or math. Besides they thought that their child could find a job and have a family, that he had any difficulty to use public transports or to take care of himself. They also considered to have any

difficulty to pay attention to other sons, to have less friends, to argue no more at home or to refuse job's opportunities, because the child's illness.

It was interesting to note as the father is fully involved and very present in the same way as the mother.

Figures 1, 2 represent the average scores of the 4 subscales of the questionnaire for

the group of mothers and fathers, respectively, according to the parameter of the frequency and importance.

Discussion

Celiac disease is a chronic disease transmitted by genetic way and because the only

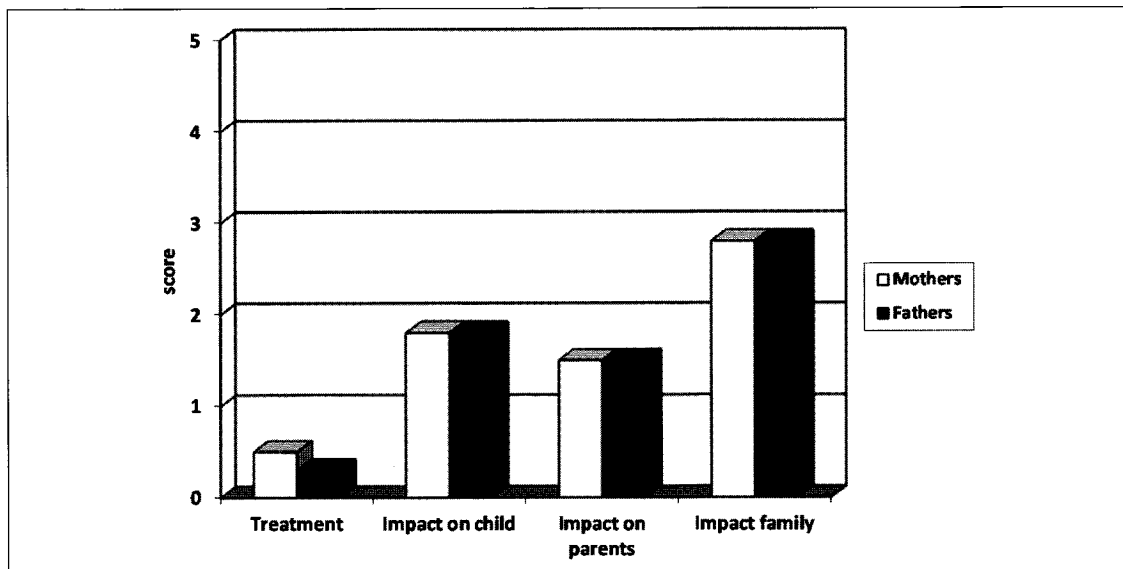


Figure 1.—Subscale scores of mothers' and fathers' groups for the frequency parameter.

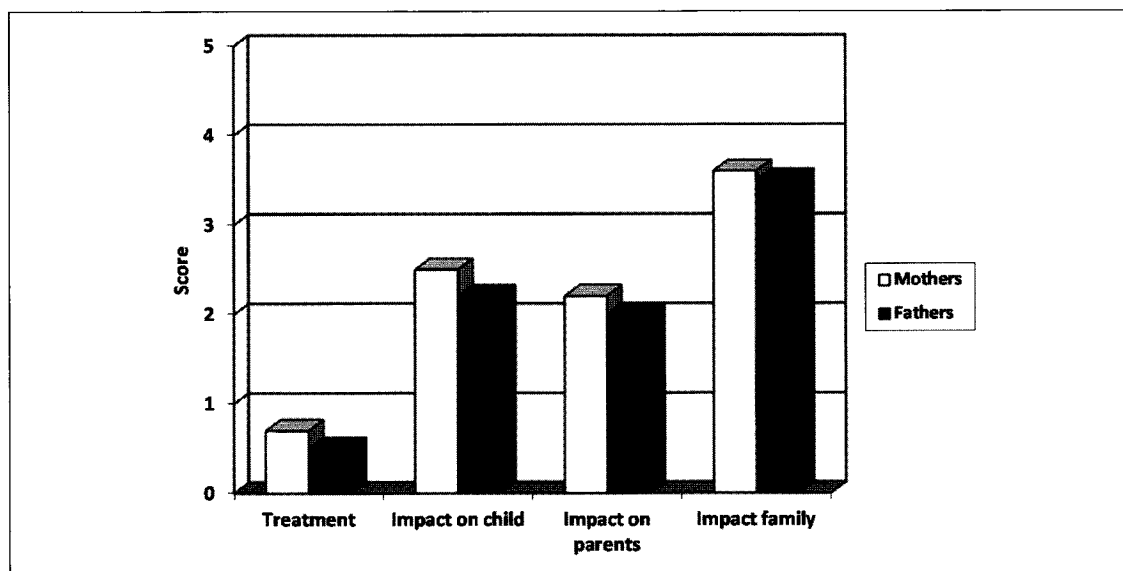


Figure 2.—Subscale scores of mothers' and fathers' groups for the importance parameter.

treatment is always the gluten-free diet, it could have important psychological implications.^{1-5, 10} The symptoms of celiac disease can be very different and often the symptoms in children are not occur in the digestive system, but in other forms: irritability, sadness, apathy, aggression.¹⁷

There are few studies evaluating the impact of the diagnosis of celiac disease and gluten free diet on quality of life in children and their families.^{7, 11-13}

In recent years there has been a substantial increase in attention to the psychological dimension linked to celiac disease; this is due to the potential impact that it can have on the development and overall functioning of the child.^{3, 8-10}

A chronic diagnosis, such as celiac disease, projects the parents immediately into the future: they are concerned about the future, would be able to check it, perhaps to avoid to their celiac sons to live gluten-free experiences of denial and limitation.¹²⁻¹⁴

Children have to learn to tell their waivers to classmates and friends: they have to learn some habits that lead them to govern relations with peers, sometimes difficult questions about the disease, the gluten, the duty "to refrain from eating as others".¹⁶⁻¹⁹

This study shows that celiac disease is a condition that has a significant impact on both the child and his family.

All families at the moment of discovery of the diagnosis have experienced before a sense of relief, and after a shock-phase related to the need to readjust the feeding behavior, and therefore the familiar, social, and relational ones. The family, with the discovery of the disease, could react with a denial of the disease, it could be disoriented, angry and disappointed. Especially the mothers described the first stage as the most distressing, the sensation to the knowledge of diagnosis was defined as «feel the world collapse on me». Parents try to cope with this particular moment with behaviors of continuous attention towards exploration of the environment by the child and with anxious modalities that sometimes can determine perturbations in the future development. Celiac disease is experienced

differently depending on the age where the diagnosis is made: parents of children aged between 2 and 6 years, with early diagnosis, see their children sad and apathetic, almost with an attitude of isolation, and it is due mainly to physical discomfort. Parents of children aged between 7 and 10 years, note in their children anxiety, sadness, irritability, restlessness; these behaviors arise because in this period the celiac child leaves the family context and begins to participate at scholar and social life. The difficulties of maintaining the gluten-free diet seem to be absent when the child is into the family, but appear significantly in moments of encounter and comparison with peers. The celiac child can assume in the peer group, passive and renunciative attitudes, locking himself, not going to parties of friends and hiding the condition of celiac disease in school and social environment. In cases of more pronounced disease he could refuse to follow the diet and to eat prohibited foods, just as a form of self harm and transgression. All that worries parents, as well as their son's scholar integration, because it means that they have to delegate to other figures (teachers) the welfare of their child.

Regarding the impact of disease on the whole family, it is observed that celiac disease for many attentions and precautions involved, and for fear of contamination, can sometimes limit the family life and the family holidays. But despite the difficulties, for many families the celiac disease is not an obstacle in their lives; many parents say that they go on vacation, leave, go out to dinner, going to parties. They always try to adopt tactics to ensure that their celiac child can share the same things as other children, and not perceive the diversity, that is very concerned about the parents which actually do everything to never see on the face of their child a frustration or disappointment.

There are different strategies for parents in order to address this problem: in some cases parents decide to change the diet of the whole family, others simply avoid to eat in front of their son prohibited foods, in other cases parents tend more or less consciously to change their lifestyle (reduction

of social activities and of lunches and dinners away from home).

Finally, as regard the impact of disease on their parents, they recognize difficulties to explain celiac disease to others; during the interview only few parents really know what constitutes celiac disease and practical and psychosocial difficulties that celiac child has when is away from home are many: the people's misunderstanding, incompetence, misinformation, false beliefs, the continuous explanations about the disease, and scholar integration is not always easy. Many parents, unfortunately, have complained how schools are still unprepared to accept celiac children. Many times, in fact, the mothers of celiac children choose the half-time and at lunch time collect the children from school so that they not dine with others and can eat foods containing gluten. This situation can be negative in terms of social and psychological: the child could feel differently and for this reason may also be marginalized by other classmates.

So the knowledge of celiac disease is important for the school system combined with an appropriate program on relationship skills among peers, with the aim to inform and educate children and teachers about various aspects of celiac disease, that is presented as an individual particularity instead of a diversity. This can ensure a better quality of life and could be a way to ensure a better integration in the class group, to foster socialization, to reinforce the image that the child has of himself and to feel himself like his peers.

Conclusions

The results obtained by administration of Impact Scale of Childhood Diseases to parents showed that subjects in developmental age with celiac disease could have difficulty on emotional level that affect child development and the whole family context. Data analysis showed that the period after the diagnosis is the most critical, parents as caregivers, defined as the role of continuous support recognized by their son, have

to develop new mechanisms to cope with celiac condition, because they feel involved under the direct responsibility towards children and their needs.

Acceptance of the illness by the child depends mainly by how much and how this has been accepted by parents. The family that is adapted to the illness is a family in which emotional burden and child's care are well distributed between the two spouses. In such families, parents have learned to handle frustrations, to control emotions, to communicate openly difficulties, in addition to manage the disease together. Is necessary to highlight the importance that their mutual interactions can affect the physical, psychological and social adaptation of child and his family. From the research is emerged as the psychological reaction of children with celiac disease is result of the interaction of specific factors, among which the most relevant are: the age of diagnosis (if it is early, at the time of weaning, celiac disease is easily integrated into the lifestyle of the child), the personal story of illness, to accept the idea to observe the gluten-free diet for all his life (it is more difficult to accept change if celiac disease not manifest itself in a salient way) and the reaction of the family system. From the combination of these factors depends the child's response to the diagnosis of celiac disease.

Doctors should be also particularly attentive to the psychosocial sphere, trying to understand the psychological reactions that the experience of a chronic illness involves both the child and the family.

The right supports can help children and their families to promote and increase their adaptation to celiac disease, and thus improve their quality of life.

Riassunto

Qualità della vita nell'età dello sviluppo in bambini affetti da malattia celiaca

Obiettivo. I momenti che seguono la diagnosi della malattia celiaca e le prime fasi della dieta priva di glutine sono estremamente difficili e complesse per i genitori e il bambino, in quanto si trovano ad affrontare un cambiamento importante scandito

dall'abnegazione e la privazione. L'obiettivo principale di questa ricerca è quello di valutare l'impatto della malattia celiaca sulla qualità della vita in soggetti in età evolutiva, prendendo in considerazione le percezioni dei genitori sulla malattia del bambino, con l'obiettivo di evidenziare l'effetto della malattia sul bambino e la intera famiglia.

Metodi. Lo studio ha incluso entrambi i genitori di 45 bambini di età compresa fra 2 e 10 anni, con celiachia. Per valutare l'effetto della malattia celiaca sullo stile di vita dei bambini affetti e delle loro famiglie è stato utilizzato, dopo aver adattato al contesto italiano, la Scala Impatto delle malattie infantili di Hoare e Russell (1995). Questo studio dimostra che la celiachia è una condizione che ha un impatto significativo sia sul bambino e la sua famiglia.

Risultati e conclusioni. I risultati ottenuti con la somministrazione di Scala Impatto delle malattie infantili ai genitori hanno mostrato che i soggetti in età evolutiva con la celiachia potrebbero avere difficoltà a livello emotivo che influenzano lo sviluppo del bambino e il contesto dell'intera famiglia. L'accettazione della malattia da parte del bambino dipende principalmente da quanto e come questa è stata accettata dai genitori.

Parole chiave: Malattia celiaca—Qualità della vita—Bambino.

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